

ANGLIA RUSKIN UNIVERSITY

FACULTY OF HEALTH, EDUCATION, MEDICINE
AND SOCIAL CARE

DISABLED PEOPLE'S USER-LED ORGANISATIONS: PAST,
PRESENT AND A SECURE FUTURE?

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ABSTRACT

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This thesis investigates disabled people's user-led organisations (DPULOs) in the UK using the themes of: historical roots; structures and characteristics; key challenges; and future opportunities. The economic downturn in 2008 resulted in cuts to DPULOs creating a market for social care services and competition between DPULOs and other sectors. An imbalance of power relationships with financial stakeholders has created an environment where DPULOs have found it increasingly difficult to develop services and remain viable.

The aim of the study was to identify the factors that might support the future security of DPULOs. The study draws on the transformative paradigm (Mertens, 2007) and is firmly located within the disability community and led by a disabled researcher. The research was a two-stage sequential design with data collected through semi-structured interviews with 12 chief executive officers (CEOs) of DPULOs, the findings of which informed a wider survey across DPULOs in the UK.

The research shows that power has shifted over time, but during economic austerity, 'value for money' is given more importance than experiential knowledge, leaving DPULOs vulnerable. Some values remain consistent including independent living (IL) and the social model of disability although equality is now seen as more important. While the unique and core aspect of DPULOs is experiential knowledge, knowledge in 'business' development is lacking in many DPULOs, who need to upskill their workforce or attract people with these skills onto their boards. The current definitional inadequacy of a DPULO is highlighted as focusing on internal characteristics at the expense of external power relations between DPULOs and their funders.

The study data suggests that for DPULOs to thrive, the Office for Disability Issues (ODI) needs to move beyond mechanistic criteria for what constitutes a DPULO and acknowledge the wider changes both within and external to DPULOs as well as changes within the disability community as a whole.

Keywords: Disabled People's User-led Organisations, DPULOs, Equality, Independent Living, The Social Model of Disability, Disability Studies, Disabled people, User-Led, Transformative Paradigm.

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LIST OF ACRONYMS

ADP	Association of Disabled Professionals
APU	Anglia Polytechnic University
ARU	Anglia Ruskin University
BA	Bachelor of Arts
BCODP	British Council of Organisations of Disabled People
BSI	British Standards Institute
CEO	Chief executive officer
CIL	Centre for independent, integrated or inclusive living
CRM	Civil rights movement
DA	Disability Alliance
DCIL	Derbyshire Centre for Integrated Living
DCDP	Derbyshire Coalition of Disabled People
DDA	Disability Discrimination Act
DDPO	Deaf and disabled people's organisation
DPO	Disabled people's organisation
DH	Department of Health
DIG	Disabled Income Group
DPI	Disabled People's International
DPULO	Disabled people's user-led organisation
DRC	Disability Rights Commission
DRTF	Disability Rights Task Force
DSA	Disabled Student Allowance
DWP	Department of Work and Pensions
ECDP	Essex Coalition of Disabled People
FE	Further education
FREP	Faculty Research Ethics Panel
HCIL	Hampshire Centre for Independent Living
HE	Higher education
HL	House of Lords
IL	Independent living
ILC	Independent Living Committee
ILF	Independent Living Fund
ILM	Independent Living Movement
ILRU	Independent Living Research Utilization
ISO	International Organization for Standardization
IYDP	International Year of Disabled Persons

LIST OF ACRONYMS

MA	Master of Arts
NCDP	Norfolk Coalition of Disabled People
NCIL	National Centre for Independent Living
NCVO	National Council for Voluntary Organisations
ODI	Office for Disability Issues
PDF	Portable document format
PDSP	Physically Disabled Students' Program
PMSU	Prime Minister's Strategy Unit
QMS	Quality management system
RI	Rehabilitation International
RSA	Rehabilitation Services Administration
SCIE	Social Care Institute for Excellence
SENDPO	South East Network of Disabled People's Organisations
SIA	Spinal Injuries Association
SOL	Shaping Our Lives
SPDR	Severe proliferative diabetic retinopathy
SPK	Simultaneous pancreas and kidney
ULO	User-led organisation
UPIAS	Union of the Physically Impaired Against Segregation
UKDPC	UK Disabled People's Council
WASU	Worcestershire Association of Service Users
WCVA	Welsh Council for Voluntary Action

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- II. Steven Wayne Carey

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CHAPTER 1

CHAPTER 1: INTRODUCTION

1.1 Introduction

The inspiration for this thesis came from my lived experience as a disabled person and the knowledge I gained as the chairman, trustee and a member of a disabled people's user-led organisation (DPULO).

My personal journey into disability started in April 1989 when I began to suffer from the long-term effects of type 1 diabetes mellitus (see: Centofani, 1995; Lee, Wong and Sabanayagam, 2015; NHS Choices, 2017a). I experienced vitreous haemorrhages in both my eyes and was diagnosed with severe proliferative diabetic retinopathy (SPDR) (see: Lee, Wong and Sabanayagam, 2015). I received vitreoretinal surgery (see: NHS Choices, 2017b) but this failed to reverse my sight loss and I was registered as severely sight impaired (blind) in July 1989. My employer forced me to leave my job because it was felt that I could no longer fulfil my duties and responsibilities as a Further Education (FE) instructor.

At about the same time as my sight loss occurred, I was rushed to The Royal London Hospital in a coma where I was diagnosed with chronic kidney failure as a result of diabetic complications and high blood pressure. I was treated with haemodialysis three times a week and a strict low protein diet to reduce the chance of further medical complications (see: Narres et al., 2016).

While in hospital, I began, for the first time, to gain an insight into the discrimination experienced by disabled people. For example, I was compelled to sign medical consent forms concerning my treatment without full knowledge of the content as the forms were not available in accessible formats. In addition, I felt isolated as the medical staff responsible for my care did not appear to understand how to support me as a blind hospital patient.

During the following year, I endured the combined disabling effects of sight loss, kidney failure and haemodialysis. However, in February 1990 I was placed on the waiting list for a new kidney and underwent transplant surgery three months later when a donated kidney became available (see: NHS Choices, 2017c).

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Although I felt that the reaction of the medical staff to my situation was more positive during this spell of treatment, I still suffered a similar level of discrimination as I had experienced in 1989 (Northway, 1997; Scullian, 1999).

After a period of rehabilitation, I felt ready to consider my potential for future employment. I concluded that to re-enter the employment marketplace I required the skills that would be acquired through a course of Higher Education (HE). I enrolled on a Bachelor of Science degree (BSc) in Information Systems at, the then named, Anglia Polytechnic University (APU). I found undertaking the course difficult as, for instance, the teaching materials were only available in print; the campus was largely inaccessible; and the academic staff were, apparently, untrained in the support of disabled students.

In spite of these difficulties, I graduated with a 2:1 honours degree in April 1996. On reflection, I concluded that my sight loss gave me the opportunity to undertake a university education, something that had always been a personal ambition. After graduation, APU employed me on a fixed-term contract to research the information needs of disabled students in light of the introduction of The Disability Discrimination Act (DDA) in 1995. On completion of this contract, APU offered me permanent employment as the manager of a new transcription service that would be used by both university staff and disabled students.

Subsequently, I was encouraged by a senior member of the APU academic staff to undertake an MA in Managing Disability Services. Unlike the BSc, the MA was more accessible to me because: the university had become more adept at supporting disabled students; information in alternative formats was now readily available; and, the course leader was a disability activist and thus very aware of the needs of disabled people. I graduated with an MA in July 2006.

While undertaking my university education and employment, I became aware of the work of The Essex Coalition of Disabled People (ECDP). I was encouraged to join the organisation as a full member and subsequently was appointed to serve on the board as a director/trustee. I became familiar with ECDPs guiding values that included the social model of disability and the principles of independent living (IL) (Oliver, 1990a, 1990b; Barnes, 2012).

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In 2005, I was unanimously elected by the trustees to the position of board chairman and was responsible for the appointment of a new chief executive officer (CEO) in 2006. As chairman of ECDP, I became familiar with the burgeoning problems faced by my organisation in areas such as: competition with local and national charities and service providers from both the voluntary and private sectors; local and national government funding cuts; and, the rationalisation of contracts for disability support services. Anecdotal evidence also suggested that other DPULOs were experiencing similar problems.

In 2009, I again began to suffer from the effects of chronic kidney failure. However, on this occasion I was put on a low protein diet but avoided undergoing haemodialysis (see: Narres et al., 2016). I was placed on the list for, what was then considered to be a novel procedure, of a simultaneous pancreas-kidney (SPK) transplant and underwent surgery when suitable organs became available in July 2010. I returned to work and resumed my duties as chairman at ECDP in November 2010.

While undertaking my role as chairman of ECDP I realised that local and national government financial restraint had resulted in a reduction of funding to my organisation. The relationship between ECDP and its funding authorities had fundamentally changed. In addition, ECDP started to lose contracts for social care services through competition with other DPULOs, national charities and voluntary and private sector service providers. Consequently, ECDP found it increasingly difficult to maintain and expand social care services and to support its clients. I concluded that for ECDP to survive and prosper, operational changes would be required.

I investigated other DPULO structural models but concluded that there was nothing obvious available that might improve ECDP's ability to maintain and expand its services. I therefore considered that it would be necessary to investigate the factors that might support the future security of DPULOs. I was then encouraged by an old colleague, at the now renamed, Anglia Ruskin University (ARU) to undertake study in this area as a doctoral student.

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1.2 Key aim and objectives

The key aim of this study is to identify the factors that might support DPULOs in the UK to survive and thrive into the future. The objectives are as follows:

To critically analyse the literature on the historical construct of disablism.

To evaluate how the emergence of dissident discourses of disability rights influenced the development of DPULOs.

To investigate the terminologies associated with disabled people and their organisations.

To identify the operational structure of DPULOs.

To identify the values and principles inherent within DPULOs.

To critically analyse the effect of UK government policies on DPULOs.

To investigate the challenges faced by DPULOs.

To identify the key characteristics of DPULOs.

1.3 The structure

The structure of this thesis is as follows:

1.3.1 Chapter 2: Literature review 1:

Disabled people and their organisations – 1962 to 1994 inclusive

This chapter investigates the development by disabled people in the USA of the Independent Living Movement (ILM), the subsequent establishment of centres for independent living (CILs) and the impact of these on the disability movement in the UK. The chapter also examines the circumstances that influenced the establishment and development of organisations that were run and controlled by disabled people

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in the UK. A detailed analysis of the individual and social models of disability is provided, as is a review of the social construct of disability and how this has had an impact on the lives of disabled people in the UK.

1.3.2 Chapter 3: Literature review 2:

Disabled people and their organisations - 1995 to 2015 inclusive

The second literature review chapter explores the development of disabled people's organisations in the UK, their terminologies, their organisational characteristics and the services they offer to disabled people and other clients. The financial constraints imposed by local and national government on these organisations are also investigated as well as funding opportunities that might improve their future sustainability.

1.3.3 Chapter 4: Conceptual framework and methodology

Initially, this chapter provides a definition of the term 'conceptual framework'. The limitations and boundaries of the research are discussed and a conceptual framework considered to be applicable to this study is then developed. This process informs the identification of the research questions and the selection of an appropriate research methodology.

This chapter then examines the ontological and epistemological conventions of a range of research paradigms and supports the selection of an appropriate approach for this study. The ontology, epistemology, methodology, axiology and methods employed in the chosen paradigm are explored.

1.3.4 Chapter 5: Research design

This chapter describes the research design process, the data collection methods selected and the ethical issues inherent in this study. Data was collected through a two-stage, mixed methods research design consisting of semi-structured interviews with, and a survey of, the CEOs of UK-based DPULOs. The applicability to this research of the concepts of reliability, validity, credibility, transferability, dependability and confirmability are also discussed

CHAPTER 1

1.3.5 Chapter 6: Findings 1 - Semi-structured interviews

This chapter initially re-examines the methods of analysis and presentation that might be appropriate for the data collected during the semi-structured interviews of stage 1 of the research. The method selected provided the basis for the analysis of the interviews and out of this process the research themes emerged. The key findings from this analysis are presented and used to inform the design of the stage 2 survey.

1.3.6 Chapter 7: Findings 2 - Survey

This chapter presents the survey data from stage 2, its analysis and the resulting key findings.

1.3.7 Chapter 8: Discussion

This chapter combines the findings from both the stage 1 semi-structured interviews and the stage 2 survey. The results are discussed in relation to my lived experience and knowledge as a disabled person and the two literature review chapters. The characteristics of DPULOs and the factors that might help these organisations to survive and thrive into the future are discussed in terms of the concepts of 'power', 'values' and 'knowledge' (SOL, 2009, cited in Bott, Sweeny and Watts, 2013).

1.3.8 Chapter 9: Conclusions

This chapter presents the contribution to knowledge and the contribution to professional practice. The research questions are answered and topics for future research are suggested. In addition, reflections on my journey as a result of undertaking this study as a researcher with severe sight loss and the limitations of the research are explored.

CHAPTER 1

1.4 Summary

This chapter has shown how my lived experience as a disabled person and the knowledge I have gained as the chairman, trustee and a member of a DPULO inspired this thesis.

The aims and a brief description of the chapters in this study are presented.

The next chapter is the first of two literature review chapters that investigates the key events that affected disabled people and their organisations during the period of 1962 to 1994 inclusive.

CHAPTER 2

CHAPTER 2: LITERATURE REVIEW 1: DISABLED PEOPLE AND THEIR ORGANISATIONS – 1962 – 1994 INCLUSIVE

2.1 Introduction

In the last chapter, I discussed the background and the factors that inspired me to embark on this study. In addition, I provided a brief description of the aims and the contents of the nine chapters in this thesis.

The following two chapters (literature review 1 and 2) provide a chronological analysis of the literature concerning disabled people and their organisations in the UK from the year 1963 onwards. The literature review has been divided into two chapters as I felt this structure highlighted the changes that occurred in the establishment of these organisations and would enable the reader to better conceptualise the factors that influenced their subsequent development.

Literature review 1 (chapter 2) covers the time period 1962 to 1994 inclusive and investigates the circumstances that influenced the establishment and initial development of organisations run and controlled by disabled people in the UK. In contrast, literature review 2 (chapter 3) covers the time period 1995 onwards which marked the implementation of specific disability legislation and investigates the key structures and characteristics of Disabled Peoples User Led Organisations (DPULO) in the UK. In addition, the chapter explores the ways in which changes in the political, economic and policy landscape have had an impact on the ability of these organisations to survive and prosper.

This chapter will investigate the development by disabled people in the USA of the Independent Living Movement (ILM) and the subsequent establishment of centres for independent living (CILs) during the 1960s and 1970s. I consider that this is important as I have become aware that the development of organisations run and controlled by disabled people in the UK appeared to have been significantly influenced by the activities of the ILM in the USA (see for instance: Evans, 2003; Pridmore, 2006; Barnes, 2007).

In addition, I will explore the circumstances that influenced the establishment

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in the UK of the Union of the Physically Impaired Against Segregation (UPIAS) in 1974 and the ensuing development of organisations that were run and controlled by disabled people.

I will also provide a detailed analysis of the individual and social models of disability that were initially developed by the disabled academic Michael (Mike) Oliver (1983). In addition, I will review the social construct of disability and how this has had an impact on my life as a disabled person.

2.2 Timeline of key events from 1962 to 1990

The following timeline provides an outline of the key dates in this chapter.

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KEY

Blue – Events pertaining to UK

Red – Events pertaining to USA

Green – International events

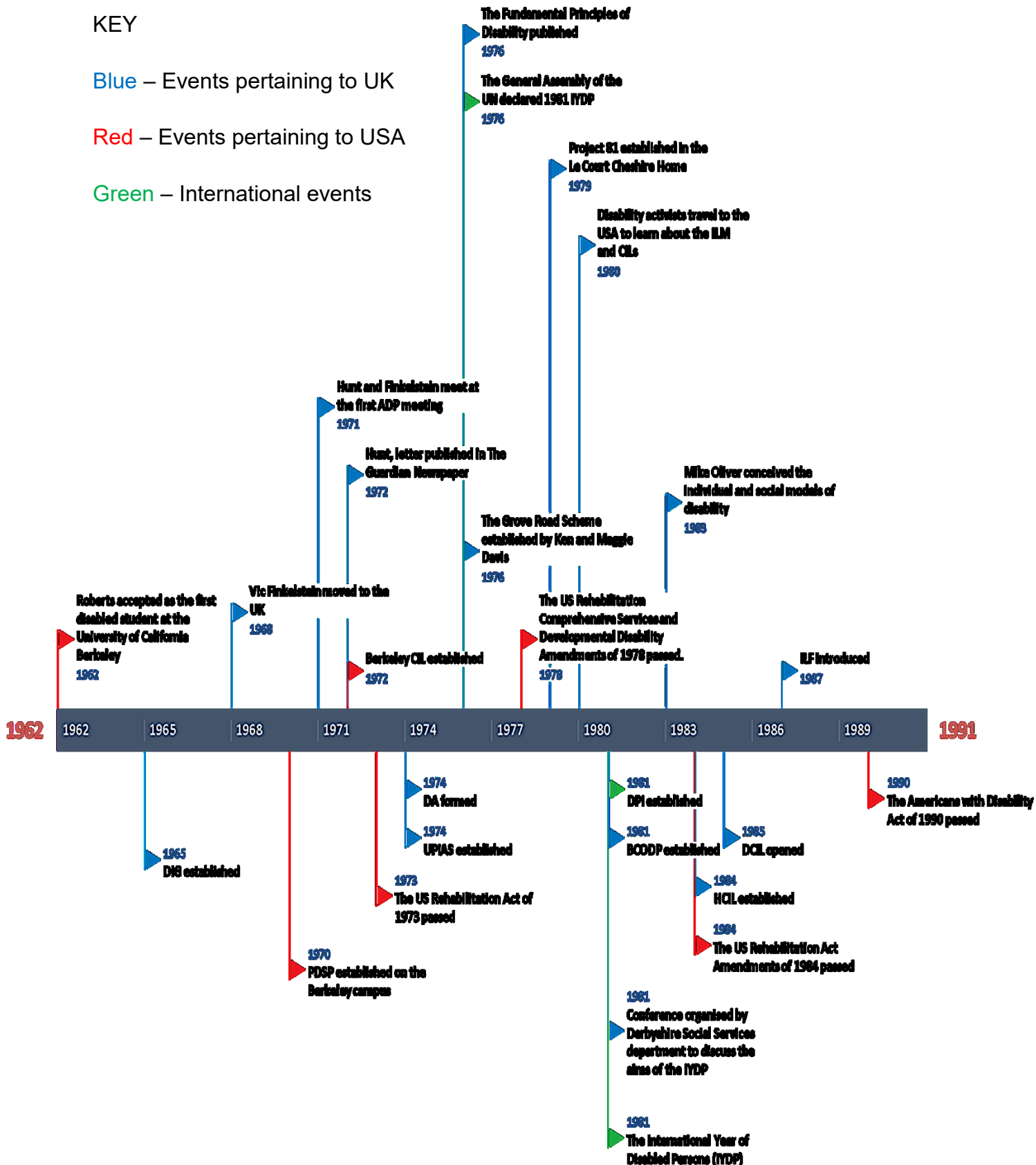


Figure 1: Timeline of key events in the development of DPULOs 1962-1990

CHAPTER 2

2.3 The Independent Living Movement (ILM) in the USA

During the second half of the 20th century, the Independent Living Movement (ILM) in the USA had close links with the development of the civil rights movement (CRM) (see for instance: McDonald and Oxford, 1995; Reay-Young, 2001; Nielsen, 2012). McDonald and Oxford (1995, p.1) noted that African Americans suffered 'disgraceful treatment based on bigotry and erroneous stereotypes in housing, education, transportation, and employment'. McDonald and Oxford (1995) also claimed that these issues were similar to those experienced within the USA by disabled people. Consequently, the strategies and tactics employed by the ILM to advance the struggle for equality for disabled people were similar to those of the CRM (McDonald and Oxford, 1995).

In 1962, Ed Roberts was one of the first severely disabled students to be allowed to attend a university in the USA (Zukas, 1975; Penney and Bassman, 2007). Previously, he had been rejected by the California Department of Rehabilitation for financial assistance to attend college as he was considered to be 'too disabled to work' (McDonald and Oxford, 1995, p.2). However, following publicity about his plight, financial aid was approved by the State of California (McDonald and Oxford, 1995). After successful completion of his studies at the College of San Mateo, Ed Roberts was accepted for admission to the University of California at Berkeley 'after initial resistance on the part of the university' (McDonald and Oxford, 1995, p.2).

As a result of the severity of Ed Roberts' impairment, the university concluded that the 'only feasible living arrangement would be a room at the Student Health Service, Cowell Hospital on Campus' (Zukas, 1975, p.2). This was because the university had no other accessible student accommodation (Zukas, 1975; McDonald and Oxford, 1995). By 1966, two more severely disabled students were resident in the Cowell Hospital and this increased to a total of 12 by 1969 (Zukas, 1975). This accommodation was subsequently established as the Cowell Residence Program and was supported financially by the California Department of Rehabilitation (Zukas, 1975; Dutta and Kundu, 2008).

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The Cowell residents became more politically aware as they realised the degree to which the hospital medical and rehabilitation staff had taken control over their lives (Zukas, 1975; Brown, 2001).

In addition, they became conscious that the ongoing political struggles of the black and student populations were also relevant to the lives of disabled people (Zukas, 1975). Subsequently, the Cowell residents decided to call themselves the 'Rolling Quads' and began to protest against the lack of physical access on Campus and within the City of Berkeley (McDonald and Oxford, 1995, p.3). By 1969, these issues were becoming more pressing for some of the Cowell residents as they were approaching the end of their academic studies and would be required to move out into the community (Zukas, 1975; McDonald and Oxford, 1995).

In order to address these concerns, the Cowell residents designed their own strategies of independent living class under the university's group studies programme (Zukas, 1975; Dutta and Kundu, 2008). It became apparent that developing and operating such a class would be costly and adequate funding would be difficult to obtain, so the residents put on hold the establishment of the necessary support services (Zukas, 1975). However, Ed Roberts became aware of potential funding from the Federal Office of Education that would provide a programme of services to support the needs of the disabled students on the Berkeley Campus (Zukas, 1975; Dutta and Kundu, 2008). Consequently, the Cowell residents envisioned the creation of a 'Physically Disabled Students' Program (PDSP)' that would provide a 'holistic, integrated approach providing a comprehensive array of services in recognition of the fact that disabled people' were 'likely to have a variety of needs' (Zukas, 1975, p.3). It was envisaged that the services provided would include 'an attendant referral service and provision for emergency attendant care, a wheelchair repair service, and an advocacy component devoted to helping disabled students deal with University related matters' (Zukas, 1975, p.3). The funding proposal for the development of the PDSP also included three guiding principles:

- '1. Those who know best the needs of disabled people and how to meet those needs are the disabled people themselves.*
 - 2. The needs of the disabled can be met most effectively by comprehensive programmes which provide a variety of services.*
 - 3. Disabled people should be integrated fully into their community'*
- (Zukas, 1975, p.3).

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Following receipt of funding, the PDSP opened in the autumn of 1970 with staff that included a number who had a range of physical and sensory impairments (Zukas, 1975). The creation of the PDSP allowed the disabled students from Cowell to move out into the community (Zukas, 1975; Dutta and Kundu, 2008). Initially, the services provided by the PDSP had been intended for disabled students only (Zukas, 1975). However, as news of the service spread, requests for assistance came from disabled members of the local community who were not students (Zukas, 1975). By the spring of 1971, there were claims that the services provided by the PDSP to the local community had started to severely affect those services provided to the students (Zukas, 1975; Dutta and Kundu, 2008).

Consequently, beginning in May 1971, a group that consisted of interested disabled people, both students and non-students, started to hold discussions about the provision of community-based services similar to, but separated from, those provided by PDSP (Zukas, 1975; Dutta and Kundu, 2008). Subsequently, the Centre for Independent Living (CIL) was established in the Spring of 1972 in Berkeley (McDonald and Oxford, 1995). While initial funding proved difficult to identify, the Rehabilitation Services Administration (RSA) awarded the CIL a grant of 50,000 US dollars to initiate the development of comprehensive support services for disabled people in the local area (Brown, 2001; Curtis, 2001, cited in Dutta and Kundu, 2008). In addition, the CIL pursued a successful funding strategy based on the regular receipt of relatively small grants that allowed a rapid expansion in service provision (Zukas, 1975). Dutta and Kundu (2008, p.401) noted that the services eventually provided by the CIL included 'peer counselling, advocacy, independent living skills training, attendant referral, transportation, health maintenance counselling, housing referral and wheelchair repair'. As a result, McDonald and Oxford (1995, p.3) claimed that the Berkeley CIL 'became the model for every such centre in the country today'.

Starting with the Rehabilitation Act in 1973, a series of federal laws were passed that were intended to improve independent living provisions for disabled people (Dutta and Kundu, 2008). These laws included: The Rehabilitation Comprehensive Services and Developmental Disability Amendments of 1978 (Public Law 95-602); and The Rehabilitation Act Amendments of 1984 (Dutta and Kundu, 2008). This culminated in the passage of the Americans with Disability Act of 1990 that provided disabled people in the USA with full civil rights (Dutta and Kundu, 2008).

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Factors such as the introduction of federal legislation and the acceptance that disempowered minorities should enjoy equal rights influenced the ILM to create an expanding number of CILs (Dutta and Kundu, 2008). For example, Seekins, Enders and Innes (1999) noted that 336 CILs had been established in the USA following the inauguration of the Berkeley CIL. This expansion in numbers continued and in 2007 data provided by the Independent Living Research Utilization (ILRU) (2007, cited in Dutta and Kundu, 2008) indicated that there were, in the USA, 723 CILs providing independent living services to disabled people with a range of impairments.

On reflection, I have concluded that there appeared to be a general consensus within the literature on the development of the ILM and the establishment of CILs in the USA (see for instance: Zukas, 1975; McDonald and Oxford, 1995; Brown, 2001; Dutta and Kundu, 2008). Of these, Dutta and Kundu (2008) also emphasised the links between the ILM and the movements towards equality followed by other groups of disadvantaged Americans. According to Dutta and Kundu (2008, p.405), the achievement of independent living enabled disabled people to move from a passive to an active position in society and thus empowered them 'in decision-making related to all aspects of life'. In summary, authors such as McDonald and Oxford (1995) and Dutta and Kundu (2008) have provided compelling evidence that the struggle for disability rights and the subsequent expansion in the number of CILs would not have transpired in the same way without the parallel influences of student protests and the wider civil rights movement. Therefore, I believe that without these influences the development of the ILM would not have progressed as rapidly as actually occurred and the implementation of American disability rights legislation would have been delayed. These events had a significant impact on the development of organisations run and controlled by disabled people in the UK.

These developments will be discussed in the following sections.

CHAPTER 2

2.4 The Union of the Physically Impaired Against Segregation (UPIAS)

The factors that led to the discrimination of disabled people in the UK have been described by authors who investigated its effects on the lived experience of disabled people (see for instance: Hunt, 1966; Finkelstein, 1980; Barnes, 1991, 2007). As early as the 1960s, disability rights campaigners in the UK were writing about the way they had perceived that society was responsible for the prejudicial treatment of disabled people and the discrimination they had experienced in many aspects of their lives (Hunt, 1966; Finkelstein, 1980). For example, Paul Hunt (1966, p.146) suggested that disabled people were viewed by society 'as unfortunate, useless, different, oppressed and sick'. Later, the South African disability activist Vic Finkelstein suggested that 'disability implies a personal tragedy, passivity and dependency' and was 'a form of group discrimination, involving constant struggles and independent action' (Finkelstein, 1980, p.1).

The views espoused by Hunt (1966) and Finkelstein (1980) were direct responses to their experiences as disabled people. Hunt, who was born in 1937 to Catholic parents in West Sussex was diagnosed with Progressive Muscular Dystrophy at the age of five and became dependent on a wheelchair by the age of 11 (Tankana, 2014). As his parents' house was not accessible, Hunt lived 'in residential institutions - Cheshire Homes - for most of his childhood and 'a considerable part of his adulthood' (Finkelstein, 2001, p.3). As a long-term occupant of the Le Court Cheshire Home, Hunt 'campaigns together with other residents for an active role in the management' of the home including its rules and regulations (Finkelstein, 2001, p.3). He also acquired knowledge about the experiences of disabled people in other parts of the world by obtaining literature about 'independent living, inclusive education and welfare benefits, through contacts with the USA and Nordic countries' (Shakespeare, 2006, p.11).

Finkelstein, who was born in Johannesburg in 1938 to Jewish parents became disabled as a result of an accident while practicing the pole-vault in which he received a spinal injury, becoming a tetraplegic and wheelchair user (Sutherland, 2011). Walsh (2007, p.4) noted that Finkelstein 'studied architecture and then psychology at university and it was there he became involved in anti-apartheid protests, fighting segregation alongside his fellow students'.

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As a consequence, he was imprisoned by the South African authorities and subsequently claimed that 'This was the only time in South Africa that things were made accessible for me' (Finkelstein, 2001, p.3). He stated that 'I was provided with a bed (political prisoners slept on a mat on the floor) and assisted with helpers because, of course, the jails were otherwise totally inaccessible' (Finkelstein, 2001, p.1). After leaving South Africa as a refugee and moving to the UK in 1968, Finkelstein commented that 'Somehow when the state has a need it does make things accessible' (Walsh, 2007, p.4).

In 1971, Paul Hunt and his wife Judy first met Vic Finkelstein and his wife Elizabeth at a founding meeting of an organisation called the Association of Disabled Professionals (ADP) (Tankana, 2014). Finkelstein (2001, p.4) pointed out that it was when he met Paul and Judy that he realised 'Although we came from different backgrounds our meeting was a meeting of like minds'. This concordant view regarding the oppression of disabled people was as a result of:

'Paul and Judy having experience of organising and mobilising disabled people, mainly within institutions, opposed all forms of discrimination and my wife and I having supported the anti-apartheid struggle of South Africa, found that we had a common agenda - how do you change an oppressive system rather than spend fruitless time appealing to the prejudiced to cease their discrimination?'
(Finkelstein, 2001, p.3).

Hunt was a member of the Disabled Income Group (DIG) that was established in 1965 (Finkelstein, 2001). The DIG was a single-issue organisation that campaigned for the introduction of universal benefits for disabled people (Shakespeare, 2006). Hunt became disillusioned with the DIG's restricted agenda and together with Finkelstein discussed the possibility of creating an organisation with the wider objective that 'mobilised disabled people at the grass-roots level against oppression' (Finkelstein, 2001, p.3). Subsequently, Hunt had a letter published in The Guardian newspaper on 20 September 1972 requesting support to set up a new organisation for disabled people (The Guardian, 1972, cited in Tankana, 2014). Finkelstein (2001) noted that following discussions with those people who had responded to Hunt's request, the UPIAS was formed in 1974.

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Also, in 1974, a separate organisation, called the Disability Alliance (DA), with similar objectives to the DIG was co-founded by the non-disabled sociologist Peter Townsend and approximately 50 disability charities (Oliver and Zarb, 1989; Shakespeare, 2006).

Finkelstein (2001, p.5) explained that the members of UPIAS 'spent about two or three years exchanging ideas' about the issues faced by disabled people and also held discussions with the DA. However, the members of UPIAS considered that the DA was a 'very elitist organisation' that had been established by 'a bunch of professional experts and some disabled people' with the primary objective of lobbying government for improved disability benefits (Finkelstein, 2001, p.5). In contrast, the key aims of the UPIAS were to 'mobilise and get disabled people involved in their own emancipation' (Finkelstein, 2001, p.5). Consequently, the membership of UPIAS distanced themselves as an organisation from the DA and published the Fundamental Principles of Disability in 1975/76 (Finkelstein, 2001). In this publication, Finkelstein provided a criticism of the DA, and Hunt produced the fundamental principles of disability (Finkelstein, 2001). Finkelstein (2001, p.5) claimed that these fundamental principles represented the UPIAS's perspective on 'the new social interpretation of disability'. The Fundamental Principles of Disability (UPIAS, 1976, p.4) publication stated that:

'disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people'.

In addition, the members of UPIAS sought to explain their experience of social oppression when they stated that 'In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society' (UPIAS, 1976, p.14). This traditional view of disabled people by society compelled activists within UPIAS (1976, p.3/4) to create new definitions for the terms 'impairment' and 'disability':

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'Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities'.

I have interpreted that the UPIAS definition of impairment suggested a biological reality for disabled people while the definition of disability provided a socially constructed perspective on the lived experience of disabled people (UPIAS, 1976; Shakespeare and Watson, 2001). However, Wendell (1996, p.57) stated that 'the distinction between the biological reality of a disability and the social construction of a disability cannot be made sharply, because the biological and social are interactive in creating disability'. As someone with severe sight loss, Wendell's (1996) biological and socially constructed aspects of disability functioning in combination, resonates with my own lived experience. For instance, I have regularly found that in interview environments, interviewers expected interaction through body language and other visual clues. Unfortunately, this socially accepted interview protocol failed to address my biological needs as a blind person and the interviewers appeared to be unable to empathise with the situation from my perspective. Consequently, while I personally have come to accept that the biological and social aspects of disability interact, there remains within society a disconnect between these two perspectives on disability.

2.5 Organisations run and controlled by disabled people in the UK

Some disability writers have suggested that the increase in activism during the 1970s encouraged disabled people living in institutions to find innovative ways to obtain more choice and control over their lives (see for instance: Lang, 2001; Evans, 2003; Pridmore, 2006). For example, in 1979, a group of residents from the Le Court Cheshire Home in Hampshire, initiated a scheme, called Project 81 - Consumer Director Housing and Care for Disabled People, which would enable them to live independently within the local community (Pridmore, 2006).

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John Evans, a founder member of Project 81, suggested that the group 'used this title because 1981 was designated the UN International Year for Disabled People' and they 'felt this would be a significant year in helping them promote the cause of Independent Living and would be helpful for them in achieving their aims of moving out of the institution' (Evans, 2003, p.2).

From 1980, inspired by the Project 81 objectives of choice and control over their lives, disability activists from the UK travelled to the USA to obtain knowledge about the ILM and the services offered by organisations such as the Berkeley CIL (Pridmore, 2006). The initial group included: 'Vic Finkelstein, radical activist, sociologist and founder of UPIAS', Rosalie Wilkins, presenter of Link, the BBC's disability television programme, and disability activist, and 'John Evans, one of the founders of Project 81' (Evans, 2003, p.1-3).

The research undertaken in the USA indicated to the members of Project 81 that the application of independent living principles would provide them with 'control over their lives, empowering themselves, taking more responsibility about what was happening to them and about developing their choices' (Pridmore, 2006, p.3). Subsequently, the 'appropriate authorities' agreed to provide the members of Project 81 'with the amount of money, agreed through an assessment, which they could then use to pay for the support they needed through employing their own personal assistants' (Evans, 2003, p.3-4). However, Evans (2003, p.4) also noted that the Project 81 objectives of obtaining independent living for its members took nearly three years to achieve because 'there was a lot of paternalism about making decisions about disabled people's lives by non-disabled people, either in Local Authorities, Charities, or National Government'.

However, the members of Project 81 were not the only group of disabled people who developed independent living initiatives in the UK during the 1970s and 1980s (Evans, 2003; Barnes, 2007). For example, in 1976 'The Grove Road Scheme' in Derbyshire was established by two disability activists, Ken and Maggie Davis, that consisted of 'a complex of flats, with 3 flats for disabled people downstairs, and 2 flats for non-disabled people upstairs' (Evans, 2003, p.5). The local housing association supported the scheme and designed rental agreements such that 'the non-disabled people living upstairs would help and assist the disabled people downstairs' (Evans, 2003, p.5).

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Unfortunately, the disabled residents did not consider The Grove Road Scheme to represent true independent living so the group later moved into their own accommodation (Evans, 2003). Following the Grove Road Scheme, Ken and Maggie Davis became key players in The Derbyshire disability movement (Evans, 2003).

In 1976, The General Assembly of the UN declared 1981 as the International Year of Disabled Persons (IYDP) (Taylor, 1981). The intended aims of the IYDP included: 'increasing global awareness of the abilities and the needs of disabled people; encouraging their fuller integration into their communities; improving preventative services; and stimulating more positive attitudes generally' (Taylor, 1981, p.1). However, disability activists claimed that the aims of the IYDP were too unrealistic and would not make any difference to the discrimination experienced by disabled people (Oliver, 1981, cited in Taylor, 1981).

The Derbyshire disability movement started to question the proclaimed aims of the IYDP (Davis and Mullender, 1993). A conference, organised by Derbyshire Social Services Department, was held in 1981 in order to review the IYDP aims (Davis and Mullender, 1993). Davis and Mullender, (1993, p.6) claimed that during the conference, speakers frequently 'referred to the need for a new approach to solving the problems of disability which were caused by the way able-bodied people had structured the world to serve and perpetuate their own interests'. One of the outcomes of the conference was the creation of a steering committee tasked with the establishment of a new organisation that would be run and controlled by disabled people (Davis and Mullender, 1993). As a result, the inaugural meeting of the Derbyshire Coalition of Disabled People (DCDP) was held on 12 December 1981. Davis and Mullender (1993, p.2) believed that this was 'the first organisation of its type to emerge in Britain'.

At a similar time to the developments in Derbyshire and Hampshire, the values espoused by UPIAS (1976) were also being adopted by others active in the UK disability rights movement (see for instance: Campbell and Oliver, 1996; Hunt, 2001; Barnes, 2007). For example, Hunt (2001, p.28) claimed that by 1981, UPIAS 'had developed a political vanguard, and it took the lead to start to build a grassroots movement'.

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Barnes (2007, p.5) noted that as a result 'British organisations controlled and run by disabled people began to multiply in the late 1970s and early 1980s'. Barnes (2007, p.6) also stated that in 1981 'seven of these organisations came together to form an umbrella body: The British Council of Organisations of Disabled People (BCODP)'. Davis and Mullender (1993) noted that the DCDP played an active role in the establishment of this organisation. The main purpose of the BCODP was to support disability organisations in campaigning 'against the institutional discrimination and prejudice that characterised the experience of living with impairment in British society' (Barnes, 2007, p.6).

Also in 1981, the Disabled People's International (DPI) was established at the World Disability Congress in Singapore (Hurst, 2005). This worldwide movement for change 'focused on the full and equal participation of disabled people in society and saw the implementation of rights as the solution' (Hurst, 2005, p.66). Davis (1996) claimed that the formation of DPI was as a direct result of the rejection by the disability practitioners of an organisation called Rehabilitation International (RI) of demands to share power with its disabled members. As a result, the BCODP became the UK representative on the DPI governing council (Davis, 1996).

Following its success, those involved in Project 81 felt it was important for them to share their experiences with other disabled people (Evans, 2003). Consequently, they founded the Hampshire Centre for Independent Living (HCIL) in 1984 with other disabled people who held similar aspirations (Evans, 2003). However, in contradiction to Davis and Mullender (1993), Evans (2003, p.6) claimed that HCIL was 'the first of its kind in the UK'. I suggest that this contradiction might have been caused by the confusing nature of the terminologies used to describe such organisations and their objectives.

One of the early aims of the DCDP was the establishment of a Centre for Independent Living (CIL) in Derbyshire (Davis and Mullender, 1993). In 1982, the DCDP and Derbyshire County Council formed a working party in order to develop such an organisation in the county (Davis and Mullender, 1993). In 1983, a second working party formulated the proposal for a Derbyshire CIL but were influenced by the members of the DCDP to replace 'the term independent living with the concept of integrated living' (Davis and Mullender, 1993, p.37).

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Subsequently, Barnes (2004a, p.5) claimed that 'in view of the dangers of misinterpretation' a small number of UK disability activists 'adopted the terms integrated or inclusive living rather than the original independent living' term as used in the USA 'to characterise the philosophy on which their activities are based'. For the DCDP, the notion of integrated living supported the assumption that:

'Whilst the nature of the barriers preventing the full social integration of disabled people in Britain are very complex, in essence it was considered that they stem from the unequal nature of the able/disabled relationship. Where barriers exist, it was recognised that they were erected on the assumption of able-bodied normality, on decisions taken by non-disabled people. It was also recognised that the design, delivery and control of services and facilities was for the disabled by the non-disabled, usually without challenge to fundamental assumptions.

The concept of integrated living grew out of this analysis. It asserts that the social integration of disabled people will follow when service delivery systems are themselves integrated, i.e., when people who have personal experience of the daily problems of disability are themselves directly involved in service design delivery and control. The approach is less to do with merely overcoming barriers, but more with removing their causes' (DCDP, 1986, cited in Davis and Mullender, 1993, p.37).

The Derbyshire Centre for Integrated Living (DCIL) was opened on 11 July 1985 (Davis and Mullender, 1993). Subsequently, the Hampshire and Derbyshire CILs began to work together, which allowed them 'to prosper and develop a cross-fertilisation of ideas' (Evans, 2003, p.6). In addition, Evans (2003, p.6-7) noted that 'This helped them to support each other, strengthening their will and determination to secure a firm platform for their infrastructural development and to look at creating a national network and movement'.

In spite of this collaboration, Evans (2003) suggested that there were some major differences in the services provided by the two organisations. The HCIL provided 'advice, information and support around personal assistance and direct payments issues' (Evans, 2003, p.7).

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The HCIL 'also produced a video, a number of articles and publications' on aspects of support for disabled people and 'were the first to provide and publish a regular newsletter covering the main topics. They also produced the first Source Book towards Independent Living in the UK' (Evans, 2003, p.7). In contrast, the DCIL 'based their approach on the 5 basic core services which were developed by the original CIL in Berkeley' (Evans, 2003, p.7). Where these were 'housing, personal assistance, mobility/transport, access and peer counselling' (Evans, 2003, p.7). The DCIL also added to these five services those of 'information and technical equipment, including support' (Evans, 2003, p.7). These services were commonly known as the Derbyshire seven basic needs and became the basis for the development of DPULOs in the UK (Evans, 2003). Subsequently, in 1989 the HCIL expanded the seven basic needs to include education and training, income and benefits, employment and advocacy services (Evans, 2003). These became known as the 12 basic needs for independent living (Davis and Mullender, 1993; Evans, 2003).

Evans (2003) emphasised that while the HCIL and the DCIL evolved differently, the services they provided all related to the principles of independent living first developed in the USA. However, Davis and Mullender (1993) and Evans (2003) pointed out that as the political and social policies of the USA and the UK were different, disabled people and their organisations in the UK had to develop an independent living system that was compatible with the British welfare state.

Consequently, the new CILs that became established emphasised the need to develop services that were based on independent living principles and the values inherent in the social model of disability (Evans, 2003). The CILs that incorporated such values into their guiding principles during the 1980s included 'Southampton, Nottingham, Bristol, Islington, Lambeth and Greenwich in London and Lothian based in Scotland' (Evans, 2003, p.8).

As a result of the influence of disabled people and their organisations at this time 'the phrase Independent Living' became 'increasingly evident in policy documents produced by health and social service professionals in the context of community care services for disabled people' (Barnes, 2003, p.6).

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For example, in 1987 the then Conservative government announced the creation of a new Independent Living Fund (ILF) that would allow disabled people to select the services that they felt they would require in order to live independently in the local community (Pridmore, 2006).

The development of such legislation supported the continuing growth of user-led services for disabled people in the UK (Barnes, 2007). For example, Barnes (2007, p.6) highlighted data produced by the BCODP (2001) which indicated that by the end of the 20th century 'it had a membership of 130 organisations representing over 400,000 disabled people.' These included local organisations such as the DCIL and national charities such as the Spinal Injuries Association (SIA).

On reflection, I have concluded that disability activists such as Vic Finkelstein and John Evans returned from the USA with a broad understanding of the principles of independent living for disabled people and the operation of CILs. I believe that this knowledge influenced the establishment and subsequent development of organisations run and controlled by disabled people in the UK. However, in my view, these were not the only influences on the development of UK disabled peoples' organisations. The new definitions of impairment and disability, as formulated by the UPIAS (1976), also provided impetus for the development of these organisations. In particular, these definitions influenced the disabled academic Mike Oliver in his conception of two new social theories of disability, the individual and social models (Oliver, 1983; 1990a; 1990b).

2.6 The individual and social models of disability

Shakespeare and Watson (2001, p.11) noted that the principles of impairment and disability were 'given academic credibility via the work of Vic Finkelstein (1980, 1981), Colin Barnes (1991) and particularly Mike Oliver (1990, 1996)'. Informed by developments in the disability rights movements, Oliver (1990a, p.1) conceived, in 1983, two theories of disability, 'the individual and social models'.

In defining the individual model of disability, Oliver (1990a, p.1) stressed that 'it locates the problem of disability within the individual' and 'it sees the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from disability'.

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In addition, Oliver (1990a) considered that the individual model was based on the concepts inherent within the personal tragedy theory of disability. French and Swain (2004, p.34) stated that 'in the personal tragedy theory, disability, or rather impairment which is equated with disability, is thought to strike individuals causing suffering and blighting lives. The tragedy is to be avoided, eradicated or normalised by all possible means'. In addition, French and Swain (2004, p.34) highlighted the widespread use of the personal tragedy view of disability in 'media representations, language, cultural beliefs, research, policy and professional practice'. For example, French and Swain (2004, p.34) claimed that the terms 'suffering' and 'sufferer' were 'the most widely used terminology in tragedy discourses to characterise the experience of disability'.

Similarly, Campbell (1990, p.3) pointed out that 'By creating a passive, tragic, dependent image of disabled people 'charities have been able to build their empires. By setting up individual, medical condition charities (often in competition with each other) and by using harrowing pictures of us plastered on billboards, they are able to raise the cash to build more segregated schools, homes and workshops which, in turn, maintain our image of dependency on them'. Barnes (1991b) and Blackmore and Hodgkins (2012) claimed that as a result, disabled people and their organisations have sustained a passionate level of opposition to practices such as charitable street collections and fundraising telethons.

While Oliver (1990a) proposed that the individual model was underpinned by the personal tragedy theory, he also envisaged a structure that included psychological and medical aspects of disability. Oliver (1990a, p.1) noted that in his view, the medical aspect of disability was, in reality, 'the medicalisation of rather than the medical model of disability'. Consequently, Oliver (1990a, p.2) indicated that he located 'the medicalisation of disability within the individual model'. Oliver (1990a, p.3) therefore disagreed with the notion of the medicalisation of disability as 'disability is a social state and not a medical condition. Hence medical intervention in, and more importantly, control over disability is inappropriate'.

Subsequently, Oliver (1996, p.31) suggested that there was in fact 'no such thing as the medical model of disability, there is instead, an individual model of disability of which medicalisation is one significant component'.

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However, Llewellyn and Hogan (2000, p.159) stated that the medical model was seen as 'the major model in defining disability'. Shakespeare (2006, p.15) suggested that the medicalisation of disability was as a result of 'the dominance of medical approaches and of medical experts' in making decisions about the lives of disabled people. Therefore, the term 'medical model' has replaced the individual model as the standard for defining the meaning of disability.

However, Oliver (1990b, p.11) had also previously proposed an alternative theoretical model that located 'the causes of disability squarely within society and social organisation'. Oliver (1983) called this new approach the social model of disability. Oliver (1983, p.23) formulated the social model, such that:

'This new paradigm involves nothing more or less fundamental than a switch away from focusing on the physical limitations of particular individuals to the way the physical and social environments impose limitations upon certain groups or categories of people'.

Finkelstein (2002, p.13) claimed that 'A good model can enable us to see something which we do not understand because in the model it can be seen from different viewpoints'. In addition, Finkelstein (2002, p.13) suggested that 'it is this multi-dimensional replica of reality that can trigger insights that we might not otherwise develop'. Consequently, the benefit of using models in this context was to support the understanding of the real-world issue of disability. Subsequently, Barnes (2007, p.4) identified three key ways in which the social model challenged the traditional understanding of disability:

'One, a social model perspective does not deny the importance or value of appropriate individually based interventions in the lives of disabled people, whether they be medically, re-habilitative, educational or employment based, but draws attention to their limitations in terms of furthering their empowerment and inclusion in a society constructed by non-disabled people for non-disabled people.'

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Two, in contrast to the conventional individual medical model of disability, it is a deliberate attempt to switch the focus away from the functional limitations of impaired individuals onto the problems caused by disabling environments, barriers and cultures.

Three, it is an holistic approach that explains specific problems experienced by disabled people in terms of the totality of disabling environments and cultures. This includes inaccessible education, information and communication systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media – films, television and newspapers’.

Barnes (2007, p.4) had therefore endorsed Oliver’s (1990b) view that the social model of disability was ‘a tool with which to gain an insight into the disabling tendencies of modern society in order to generate policies and practices to facilitate their eradication’.

However, not all those involved in writing about the issues faced by disabled people were fully supportive of a social model approach to disability (see for instance: Crow, 1996; Thomas, 1999; Shakespeare and Watson, 2001; Shakespeare, 2006). For example, Shakespeare and Watson (2001) claimed that the social model considered the physical barriers experienced by disabled people but failed to take into account the effect of their impairments such as the muscle stiffness and spasms experienced by some of those with multiple sclerosis. Oliver (2004, p.24) highlighted the five main criticisms of the social model that came ‘from within the disability movement and disability studies’. However, Oliver (2013) distilled these into two key criticisms. Firstly, Oliver (2013, p.1025) suggested that claims had been made ‘that there is no place for impairment within the social model of disability’. Secondly, it had also been alleged that ‘the social model fails to take account of difference and presents disabled people as one unitary group (Oliver, 2013, p.1025).

Oliver (2013, p.1025) concluded that the overall position held by critics was that ‘the social model is only a limited and partial explanation for what is happening to disabled people in the modern world’.

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In addition, Oliver (2013, p.1,025) noted that 'the major disability charities and many professional organisations' felt that their dominance of disabled people 'was under threat' as a direct result of the impact of the social model.

Two of the fiercest critics, Shakespeare and Watson (2001, p.9), took an extreme view and claimed that the 'social model itself has become a problem, and that it cannot be reformed'. As a consequence, Shakespeare and Watson (2001, p.9-10) concluded that 'the British version of the social model has outlived its usefulness' and 'it is time to put the whole thing to one side and start again'.

Oliver (2013, p.1,025) responded by agreeing that the social model 'does not do many of the things its opponents criticise it for not doing'. However, Oliver (2013, p.1,026) also rounded on these critics and determined that 'those who have talked down the social model' have failed 'to replace it with something more meaningful and useful'. In addition, Oliver (2013, p.1026) concluded that 'they have been rather silent in speaking out or building alternative models to address what is happening to disabled people'.

Oliver (2013, p.1025) claimed that the social model had 'become the vehicle for developing a collective disability consciousness and helped to develop and strengthen the disabled peoples' movement'. While Shakespeare and Watson (2001, p.9) remained as determined critics, they agreed that a social model approach to disability rights 'enabled the identification of a political strategy, namely barrier removal' and created a movement for change that was 'very liberating for disabled individuals'. As a result, 'disabled people began to think of themselves in a totally new way, and became empowered to mobilise, organise and work for equal citizenship' (Shakespeare and Watson, 2001, p.10).

As a disability activist and trustee of an organisation run and controlled by disabled people, I have a natural affiliation for the values inherent in the social model of disability (Oliver, 1983; Barnes, 2007). In my role as a trustee, I had personal, lived experience of how the social model had empowered disabled people through the design of inclusive policies and practices for the provision of local services (Barnes, 2007).

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For example, in 2003, I was involved in the evaluation of a strategy first initiated by my local authority that sought 'to enable and empower disabled people to express and exercise choice and control through their lives and' was 'firmly underpinned by the principles outlined in the social model of disability' (Johns et al, 2004, p.51). This programme, called The Equal Lives Strategy (Essex County Council Social Services, 2001), was designed to improve independent living and equality in the provision of social care services for disabled people living in Essex.

Although I acknowledged the views of those disability writers who had opposed the social model (Crow, 1996; Thomas, 1999; Shakespeare and Watson, 2001; Shakespeare, 2006), I believe that the disability movement in the UK and the development of organisations run and controlled by disabled people would not have emerged in the same way without Oliver's (1983) new theoretical approach to disability. In the context of this research, I believe that the values inherent in the social model of disability had empowered disabled people in the UK in a similar way to that of the ILM in the USA (Dutta and Kundu, 2008).

2.7 Summary

This chapter has reviewed the development of organisations run and controlled by disabled people. The ILM emerged in the USA during the 1960s and 1970s as a result of the activities and values of the civil rights movement and was responsible for the development of independent living principles and of CILs. In the early 1980s, UK disability activists who visited the USA returned with knowledge about the ILM and the services offered by organisations such as the Berkeley CIL. In 1976, in the UK, the UPIAS introduced new definitions for the terms 'impairment' and 'disability' which emphasised their view that society was responsible for the oppression of disabled people.

I have concluded that all of these concepts influenced the disabled academic Mike Oliver in the development of the individual and social models of disability.

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The independent living principles and social model of disability were used by the disabled peoples' movement in the UK to develop the values that subsequently underpinned their organisations. I have also concluded that the social model of disability empowered disabled people and provided the impetus for the growth of organisations in the UK run and controlled by disabled people. I described my lived experience of discrimination as a disabled person and presented my view that disability was socially constructed.

In the next chapter, I continue my investigation into the development of CILs and other organisations run and controlled by disabled people and the issue of their long-term survival considering the financial crisis in 2008 and the impact of the subsequent austerity measures introduced by local authorities.

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CHAPTER 3: LITERATURE REVIEW 2: DISABLED PEOPLE AND THEIR ORGANISATIONS – 1995 TO 2015 INCLUSIVE

3.1 Introduction

Chapter 2 investigated the emergence of the Independent Living Movement (ILM) in the USA and the subsequent development of Centres for Independent Living (CILs) in the 1960s and 1970s. The establishment of these CILs influenced the development of similar organisations in the UK, run for and by disabled people. The Union of the Physically Impaired Against Segregation (UPIAS) was established in the UK in 1974 by disability activists to promote the concept of disability rights and independent living for disabled people.

In this chapter, I will present an overview of the subsequent development of organisations run for and by disabled people, described in this thesis as disabled people's user-led organisations (DPULOs). I will highlight the contested terminologies used to describe them, as well as their organisational characteristics and the services they offer to disabled people and other clients. I will also evaluate the effect of UK government policies on these organisations in light of the financial crisis in 2008 and the impact of subsequent economic constraints while highlighting the lack of literature assessing the impact of financial austerity on DPULOs.

3.2 Timeline of key events from 1995 to 2015

The following timeline provides an outline of the key dates in this chapter.

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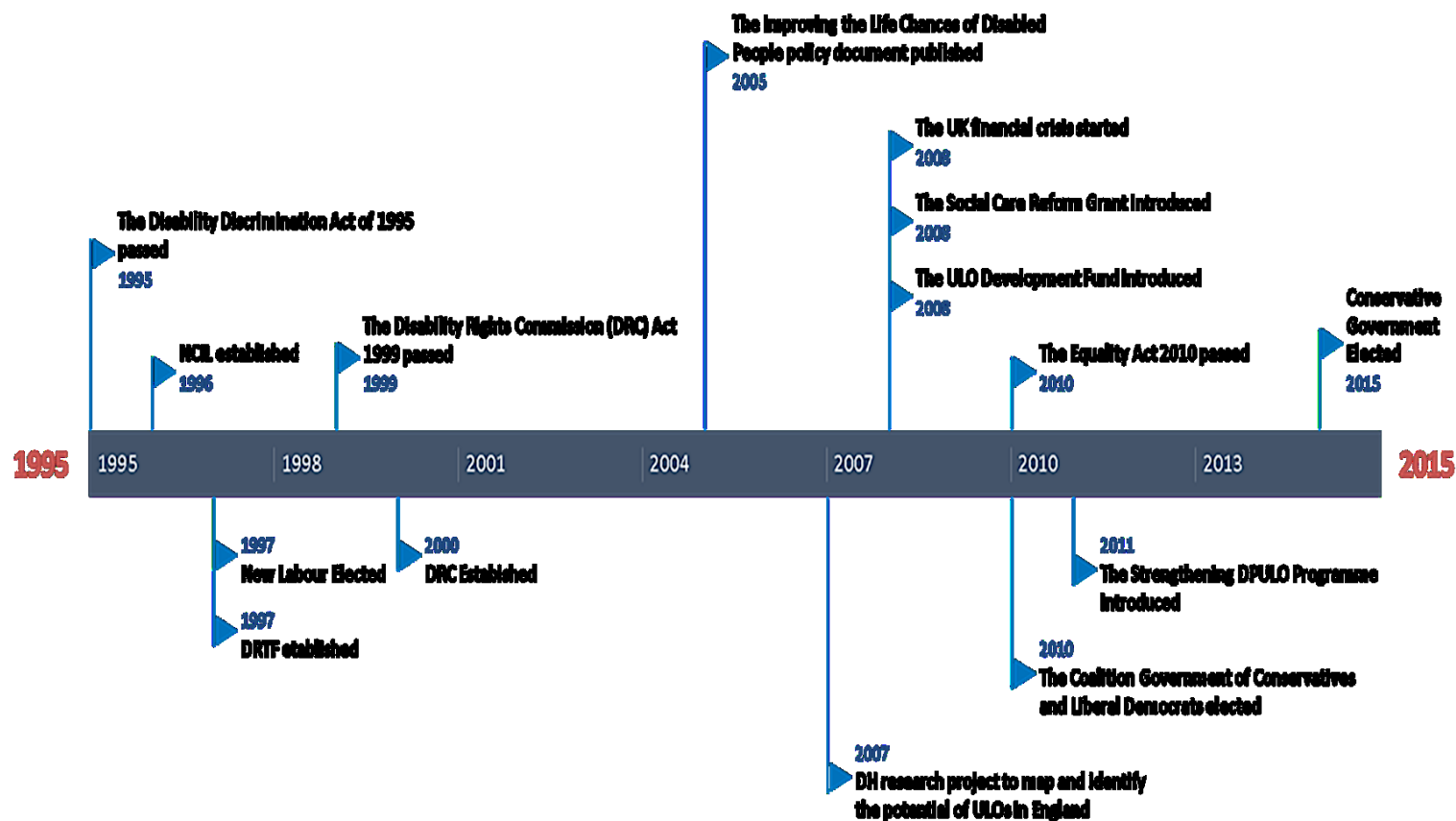


Figure 2: Timeline of key events in the development of DPULOs 1995-2015

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3.3 The development of disabled people's organisations in the UK

Political activism by the disability movement during the last decades of the 20th century as outlined in chapter 1, challenged the UK government to introduce policies that offered equal rights to disabled people (see for instance: Morris, 2005; Oliver and Barnes, 2006; Barton, 2013). For example, Barnes (2007, p.209) highlighted the prominent campaign for a change in government policy that 'increased public attention to the demand for civil rights legislation for disabled people'. These demands eventually forced the then Conservative government to introduce the Disability Discrimination Act (DDA) in 1995 (Oliver and Barnes, 2006; Morris, 2011).

Subsequently, the Community Care (Direct Payments) Act of 1996 'empowered local authorities to make direct payments to certain groups of disabled individuals; notably, adults with physical disabilities who are below retirement age' (Barnes, 2007, p.9). Such legislation prompted the establishment in 1996 of an organisation known as the National Centre for Independent Living (NCIL) by the Independent Living Committee (ILC) of the British Council of Organisations of Disabled People (BCODP) (Evans, 2003). As a result, the NCIL received financial support from the Department of Health (DH) to actively encourage local authorities to implement direct payment services for their eligible clients (Evans, 2003).

However, Oliver and Barnes (2006, p.4) claimed that there were concerns within the disability movement that the DDA legislation was 'neither comprehensive nor enforceable'. In addition, Morris (2005, p.3) suggested that the DDA was inadequate as it did 'not deliver full civil rights' for disabled people and 'in using a medical model approach to who is covered by the legislation, it limits protection from discrimination to those who meet certain definitions or levels of impairment'. In spite of such criticism, the Conservative government established a task force to ensure implementation of the legislation (Oliver and Barnes, 2006).

When a Labour government was elected in 1997, this task force was disbanded and a new one was established. The new Disability Rights Task Force (DRTF) engaged 'various "stakeholders" including representatives of organisations both for and of disabled people, parents' groups and employers' organisations' in order to provide a balanced perspective on disability rights and equality policy for disabled people (Barnes, 2007, p.209).

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The final DRTF (1999) report, *From Exclusion to Inclusion*, petitioned for changes to the DDA and the establishment of a commission that would undertake the responsibility of enforcing legislation, education and research concerning disability rights (Barnes, 2007). The introduction of the Disability Rights Commission Act 1999 resulted in the establishment of the Disability Rights Commission (DRC) in 2000. Zarb (2003, p.1) noted that 'The Commission's overall strategic objective' was to create 'a society in which all disabled people can participate fully as equal citizens'. In addition, Zarb (2003, p.7) claimed that one of the DRCs aims was to collect 'evidence to highlight existing barriers to independent living, and how this affects disabled peoples' ability to exercise other rights'.

The struggle for independent living and self-determination for disabled people was summarised in the slogan 'Nothing About Us Without Us' (Charlton, 2000). The sentiments of this slogan originated in 15th century Central European political philosophy and were adopted by the international disability rights movement in the early 1990s (Crowther, 2007). Charlton (2000, p.3) stated that 'Nothing About Us Without Us' articulated the view that 'politically active people with disabilities are beginning to proclaim that they know what is best for themselves and their community'.

Morris (2005, p.5) later concluded that the Labour government recognised the importance of independent living as a result of 'a change in attitudes towards disabled people; practical demonstrations that giving people choice and control works; and research evidence that this is an efficient use of public resources'. As a consequence, the term 'independent living' was defined by the Prime Minister's Strategy Unit (PMSU, 2005, p.58) as 'all disabled people having the same choice, control and freedom as any other citizen - at home, at work and as members of the community'.

Subsequently, following 'widespread consultation with various stakeholders including disabled people and their organisations' the *Improving the Life Chances of Disabled People* policy document was published by the Prime Minister's Strategy Unit in 2005 (Barnes, 2007, p.211). Labour Prime Minister Tony Blair, in the foreword to the policy document stated that the 'Government is committed to improving the life chances of disabled people' (PMSU, 2005, p.5).

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Barnes (2007, p.211) acknowledged the importance of this document as it supported 'a social model definition of disability and the importance of introducing policies to enable disabled people to achieve independent living'. For example, the policy document stated that 'by 2025 disabled people in Britain should have full opportunities and choices to improve their quality of life and be equal members of society' (PMSU, 2005, p.4). Under these proposals, choice and control for disabled people would become paramount with the services funded by local authorities through the implementation of individual budgets, more commonly known as direct payments (Barnes, 2007). In the Improving the Life Chances of Disabled People summary of recommendations, the Labour government proposed that 'by 2010, each locality (defined as that area covered by a council with social services responsibilities) should have a user-led organisation modelled on existing CILs (PMSU, 2005, p.91). Barnes (2007, p.212) pointed out that the Labour government intended that CILs should be 'at the heart of these policy developments'.

The Labour government claimed that 'funding for the services provided will come from Service Level Agreements with health, social services, the Department of Work and Pensions (DWP) and other agencies, and from spot purchasing of services such as disability equality training and consumer audits' (PMSU, 2005, p.91). At a minimum, it was expected that user-led organisations (ULOs) would provide 'information and advice; advocacy and peer support; assistance with self-assessment; support in using individual budgets (including cash payments) to meet needs; support to recruit and employ personal assistants; disability equality training; and consumer audits of local services' (PMSU, 2005, p.91). The Labour government also recommended that the 'case should be explored for additional resources to be bid for from the Spending Review 2006 to facilitate the development of a national network of ULOs and to support high quality services' (PMSU, 2005, p.91). The intention was to improve independent living services for disabled people as effectively as possible by utilising the resources and abilities of these ULOs.

In spite of the Labour government's intentions, Oliver and Barnes (2006, p.4) claimed that 'there is a wealth of evidence from a variety of sources, showing that existing CILs are closing down at an alarming rate'. The evidence to verify this claim has proved difficult to obtain, although Barnes (2007, p.211) pointed out that 'in 2000, research indicated that there were only eighty-four user controlled organisations providing services to disabled people'.

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In addition, the same paper noted that in 2007 there were just twenty-two CILs providing disability services (Barnes, 2007). However, there might have been a discrepancy in the numbers of organisations as a result of the use by Barnes (2007) of two different terminologies to identify disability organisations. Bott, Sweeny and Watts (2013, p.5) highlighted a ULO baseline study from 2009 that suggested that there were '66 established ULOs'. A further study in 2010 'estimated that there were around 150 ULOs in England' (Bott, Sweeny and Watts, 2013, p.5). The disparity in the numbers could be 'explained by the fact that' both studies were 'based on self-assessment' and there was a 'lack of familiarity with the design criteria amongst respondents, making it difficult to obtain an accurate or consistent measure' (Bott, Sweeney and Watts, 2013, p.5). However, Blackmore and Hodgkins (2012, p.6) created further confusion when they claimed that in 2010 'the estimated number of Disabled People's Organisations (DPOs) in England' ranged 'between 650 and 1000'. Confirmation of the problem of obtaining accurate information was provided in a House of Lords debate by Wheeler (HL, 2011) who stated that there was no known database of ULOs currently in existence. By this point a range of terms were being used to describe organisations run for and by disabled people, reflecting the different countries involved in the debates, and broader debates within the disability movement, regarding power relationships (see for instance: Barnes, 2004a; Oliver and Barnes, 2006; Barnes, 2007). In the next section, I will briefly outline some of the contested terms, all of which were search terms I needed to use to capture the complexity of the area but which moreover have implications for the ways in which statistics about such organisations were and are reported.

3.4 Definitions and characteristics of disability organisations

As reflected in the examples above, it has been suggested that the terminologies used to describe organisations run for and by disabled people has been both confused and contested (see for instance: Reay-Young, 2001; Bott, 2010; Bott, Sweeny and Watts, 2013). Reay-Young (2001, p.147) noted the confusing nature of the terminologies ascribed to these organisations when she claimed that 'The literature is replete with definitions, characteristics and ideologies' and 'is often used interchangeably, which can add to the confusion'.

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For example, Munn-Giddings et al. (2009, p.14), in reporting research undertaken in the UK, noted that the term 'user-led organisation' (ULO) was used to describe organisations that were run 'by and for people who share the same health or social condition'. Carr (2010, p.1) provided a more comprehensive definition where a ULO was 'an organisation that is run and controlled by people that use support services, including disabled people, mental health service users, people with learning difficulties, older people, and their families and carers'. In another example, a consultation document produced by Shaping Our Lives (SOL) (SOL, 2009, cited in Bott, Sweeny and Watts, 2013, p.9) used the term 'user-controlled organisation' as it was considered that this more accurately described 'the power that people who use services hold within the organisation'. However, Bott, Sweeny and Watts (2013) noted that SOL (2009) also used the acronym ULO and described three characteristics, 'values', 'power' and 'knowledge', that could be used to define such organisations. In addition, Bott, Sweeney and Watts (2013, p.9) claimed that disability organisations: should be 'based on clear *values* of independence, involvement and peer support'; should be 'uniquely identified by their *knowledge*, which is based on direct, lived experience'; and that the 'people who use services control the organisation (*power*)'

Blackmore and Hodgkins (2012 p.36) used the term 'disabled people's organisations' (DPOs) to describe such organisation in their glossary of terms, as:

'an organisation with a majority of disabled people in its membership and managing board whose objectives are to further the rights and equality of disabled people. DPOs subscribe to the social model of disability and are committed to the human rights of disabled people. DPOs work for the empowerment of disabled people either implicitly or explicitly and provide a range of activities. These are typically community based such as advice, advocacy, representation, research, policy development, campaigning, inclusive design and other initiatives'.

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The Office for Disability Issues (ODI) (ODI, 2011, cited in Bott, Sweeny and Watts, 2013, p.2) expanded the definition of a DPO by defining a disabled people's user-led organisation (DPULO) as an organisation that: was 'led and controlled by disabled people'; had 'a minimum membership of 75 per cent of disabled people on their board'; demonstrated their 'commitment to disabled people by employing disabled staff and volunteers'; and were dedicated to the principles of the social model of disability. However, Turnbull (2012) noted that this definition was extended by the ODI to include those organisations that were actively working towards achieving these objectives.

Bott, Sweeny and Watts (2013) pointed out that ULOs were structured in various ways and there was no one specific model. For example, ULOs might be structured: as 'a single organisation'; 'a formal partnership between two or more organisations'; or 'a hub and spoke model where a number of organisations contribute to the ULO at the centre' (Bott, Sweeny and Watts, 2013, p.8).

In addition, ULOs could take a number of different legal forms including: 'registered charity'; a 'company limited by guarantee'; 'a charity and a company limited by guarantee'; 'charitable incorporated organisation'; 'community interest company'; or 'social enterprise' (Bott, Sweeny and Watts, 2013, p.8). However, it was also 'the case that' some 'ULOs are not (yet) legally constituted organisations' as they 'fall beneath the lower income threshold of £25,000 used by the Charity Commission' (Bott, Sweeny and Watts, 2013, p.8). Consequently, Bott, Sweeney and Watts (2013, p.9) suggested that the characteristics and structure of these organisations could be dependent upon 'local conditions and the history of service user activism in the community'.

There was some evidence that the growth of such organisations was the result of direct action by disabled people and the impact of local conditions (Bott, Sweeney and Watts, 2013). For example, the development of my own DPULO was as a result of a partnership between disability activists and social care staff from the local authority. However the ODI requirement for at least 75% of the board members of a DPULO to be disabled seemed to me illogical as it would exclude organisations that were unable to comply even though they could be led by a majority of disabled people. In addition, I agreed with Breakthrough UK (2013) who claimed that a large percentage of disabled people in the UK were not service users.

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These debates over terminology therefore have more insidious implications than just statistics since service users who did not understand the terminologies used or the values of the disability movement might not recognise the benefits of becoming members of ULOs. Similarly, funders might not offer financial support to such organisations.

In spite of the different definitions, I felt that the characteristics of all of these types of organisations were reflected in the values, power and knowledge of a ULO as defined by SOL (2009). For the purposes of this thesis and to avoid confusion, from this point on, I will use the term now most common in the UK - 'disabled people's user-led organisations' (DPULOs) and the definition as outlined by the ODI (2011), Turnbull (2012) and Bott, Sweeny and Watts (2013).

3.5 The development of DPULOs in the UK

While confusion over the numbers of organisations run and controlled by disabled people in existence continued to influence debate within the UK disability movement, the key challenges for such organisations appeared to be focused on financial support from government agencies. Woodin (2006, p.3) stated that these challenges included: 'acute difficulties in accessing sufficient funding, thus making longer-term planning very difficult'; contracting procedures that favour 'larger organisations that offer economies of scale'; 'competition for what limited funding exists'; assistance 'from local authorities is too often ambivalent, and sometimes hostile'; and 'long-term under-investment by national and local Government'. However, in order to fulfil the Improving the Life Chances of Disabled People recommendations (PMSU, 2005), the Labour government would need to ensure that ULOs could survive and thrive.

In 2007, the Department of Health (DH) responded to the Improving the Life Chances of Disabled People policy document (PMSU, 2005) by implementing a research project, which was undertaken by Maynard Campbell, Maynard and Winchcombe (2007) to map and identify the potential of ULOs in England.

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Hudson (2008, p.34), in a summary of the project objectives, noted that the research questions used in the study were: 'what is the nature and capacity of existing ULOs and what factors appear to affect their sustainability and effectiveness?' and 'what factors inhibit or facilitate ULOs, and how far could local organisations contribute to their development?'.

In this DH document (Maynard Campbell, Maynard and Winchcombe, 2007, p.12), twenty-one design criteria were outlined that were intended to define the 'key requirements to be a viable and sustainable' ULO. The design criteria were placed into two groups. The first group consisted of values to which all ULOs should adhere. These included: 'works from a social model of disability perspective'; 'promotes independent living'; 'promotes people's human and other legal rights'; 'shaped and driven by the initiative and demand of the organisation's constituency'; 'is peer support based' (Maynard Campbell, Maynard and Winchcombe, 2007, p.12).

The second group consisted of organisation characteristics applicable to ULOs. These characteristics included: 'is a legally constituted organisation'; 'has a clear management structure'; 'is financially sustainable'; 'works with commissioners to improve commission and procurement' (Maynard Campbell, Maynard and Winchcombe, 2007, p.13). In addition, the policy document specified the minimum services that a ULO should supply in order to support independent living for disabled people (Maynard Campbell, Maynard and Winchcombe, 2007). These were in line with those previously defined in the Improving the Life Chances of Disabled People policy document (PMSU, 2005).

Hudson (2008, p.34) highlighted the key outcomes such that 'few localities appear to have an existing ULO as defined in the study'. As previously suggested, this might have been compounded by the lack of agreed understanding over what constituted a ULO. However, the research identified '647 possible local organisations' but concluded 'that many did not function as a CIL'. In areas that included ULOs, the distribution 'was locally variable' and 'over half of localities had only between one and five' ULOs while 12% of localities had no associated ULO (Hudson, 2008, p.34). In addition, Hudson (2008, p.34) pointed out that a large percentage of ULOs were established by people from single impairment groups for the purposes of 'self-help and peer support '.

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However, not many recorded their governance structures, although ULOs received most of their funding from 'local authorities and some charitable trusts' (Hudson, 2008, p.34).

In order for ULOs to thrive Hudson (2008, p.35) emphasised that further research was necessary on 'the production of national guidance, capacity building, attention to funding issues and an exploration of cost-effectiveness'. In addition, Hudson (2008, p.34-35) noted that success for ULOs depended upon 'how such organisations are treated' within the local community and the 'receptiveness of the local authority to the whole idea of involving, engaging and empowering service users' and their organisations. However, Hudson (2008, p.35) pointed out that 'despite much improvement', 'much consultation and involvement undertaken' by local authorities was cosmetic.

Hudson (2008) concluded that the DH document (Maynard Campbell, Maynard and Winchcombe, 2007) resulted in the introduction of a new funding initiative to facilitate capacity building in ULOs. The DH established the User-led Organisation Development Fund in 2008 which provided £850,000 to: 'Increase the capability and capacity of existing ULOs to meet' the specified design criteria as detailed by Maynard Campbell, Maynard and Winchcombe (2007); 'Enable the establishment of ULOs where none exist'; and 'Generate practical solutions that can be shared' (Hudson, 2008, p.35). In this initiative, the User-led Organisation Development Fund provided support for capacity building in twenty-five ULOs (Bott, Sweeny and Watts, 2013).

In addition, Bott, Sweeny and Watts (2013) highlighted the capacity building work undertaken by the DH and ODI through a new funding initiative in 2008 to the deputy regional directors for social care through the new Social Care Reform Grant. This funding initiative distributed resources to each region between the financial years 2008/9 and 2010/11 'to try to ensure there was a ULO in each local authority in each region, and to support coproduction more widely' (Bott, Sweeny and Watts, 2013, p.10).

Within the new Labour government's Improving the Life Chances of Disabled People policy document (PMSU, 2005) it was suggested that ULOs would be closely involved in the running of independent living services.

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However, a criticism might have been that the government at that time had not considered the extent to which these organisations had the capability to undertake the role. For example, at the time there was considerable uncertainty about the number of such organisations, their localities and their experiences in running services (Woodin, 2006; Barnes, 2007; Hudson, 2008).

This situation was exacerbated because the disabled peoples' movement had 'cut its teeth on oppositional politics and had little experience of participating with politicians' (Oliver and Barnes, 2006, p.8). Consequently, Oliver and Barnes (2006) pointed out that the new Labour government had worked with large national charities as the voice of disabled people rather than representatives from the movement itself. This, I suggest, removed disabled people and their organisations from the decision-making processes that the government employed (Oliver and Barnes, 2006) and it was not until the submission of the DH policy document (Maynard Campbell, Maynard and Winchcombe, 2007) that the then government became aware of the issues that ULOs were facing. It can be argued that the government should have investigated the issues earlier in the process and found solutions to the deficiencies in the network of providers that they envisaged would offer the services detailed in the policy document (PMSU, 2005). Therefore, I suggest that the financial support, including the £850,000 provided under the User-led Organisation Development Fund (Hudson, 2008), was likely to be grossly inadequate to strengthen the capabilities of established ULOs and further develop the network of organisations to fulfil the government's objectives.

3.6 The challenges faced by UK DPULOs

In spite of the Labour government's commitments, the election of the coalition government of Conservatives and Liberal Democrats in 2010 resulted in the beginning of public expenditure reductions that were expected, by Morris (2011) to disproportionately affect disabled people. In summarising her position, Morris (2011) suggested that success for the disability movement and its organisations would depend on sustainable and adequate resources to replace the reductions that would occur in local and national government funding. In support of this view, a report commissioned by the Norfolk Coalition of Disabled People (NCDP) came to similar conclusions (Edwards, 2011).

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The fears about public expenditure reductions as expressed by Edwards (2011) and Morris (2011) appeared to have been proven. A report by Inclusion London (2012), one of the few to ever focus on the impact of financial austerity on DPULOs, detailed significant funding cuts that had been experienced by London based ULOs, otherwise known as Deaf and Disabled People's Organisations (DDPOs), during 2011/12.

Having undertaken an in-depth analysis of the Inclusion London (2012) report, I realised that the findings did not accurately represent either the data collected (detailed in full in the report) or the final conclusions. The conclusions covered such areas as: developing a strategic approach by national and local government to support DDPOs; the requirement of a commitment by national and local government to better engage with DDPOs; and the addressing of specific business support needs of DDPOs. In contrast, the key findings solely covered the issues of funding cuts and closures. In addition, part of the report was confusing to the reader as the data analysis used percentages with rounding errors rather than whole numbers when discussing DDPOs (Inclusion London, 2012). In addition, the Inclusion London (2012, p.5) report appeared to differentiate between the terms 'funding' and 'income', where funding referred to revenue from local and national government sources while income referred to all revenue sources.

Since the Inclusion London (2012) report was one of the few literature sources that explored these issues for DPULOs and given that the raw data was included in the report, I undertook a more in-depth analysis of the report data as part of this research. The analysis indicated that of 54 DDPOs surveyed, some 40 (74.1%) had experienced cuts in 'funding': of these, 24 experienced 'cuts in total income' of up to 20% while the remainder experienced cuts of between 20% and 100% (Inclusion London, 2012, p.5). In addition, 31 of these DDPOs expected further cuts in 2012/13, while 23 predicted that they might experience a reduction in total income, but that at the time the survey was undertaken they lacked sufficient information to reach a conclusion (Inclusion London, 2012). The report findings stressed that 'the biggest reductions in funding' to DDPOs 'came from Local Authority funding sources' (Inclusion London, 2012, p.5). The report focused on the impact of such funding cuts rather than the need for these funding bodies to 'address the specific business support needs DDPOs have in order for them to survive and thrive' (Inclusion London, 2012, p.33).

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The report, however, also failed to address the issues of the assets held by DDPOs or the use of these assets to support service provision.

As the Inclusion London (2012) report only investigated the situation in the capital, where it can be argued more awareness and funding streams might be in place for DDPOs, I located on the Charity Commission (2012) website, four DPULOs from other areas of the UK in order to investigate their levels of income and expenditure and, in addition, their use of assets to support service provision.

These were: The Council of Disabled People Warwickshire and Coventry; Hertfordshire PASS; Leicester Centre for Integrated Living Limited; and The Derbyshire Centre for Inclusive Living. These DPULOs were selected as their data was readily accessible and provided accounting information that covered several years.

Figures 3, 4, 5 and 6 below show the total income, expenditure and assets for these DPULOs that were selected from outside of the London area (Charity Commission, 2012).

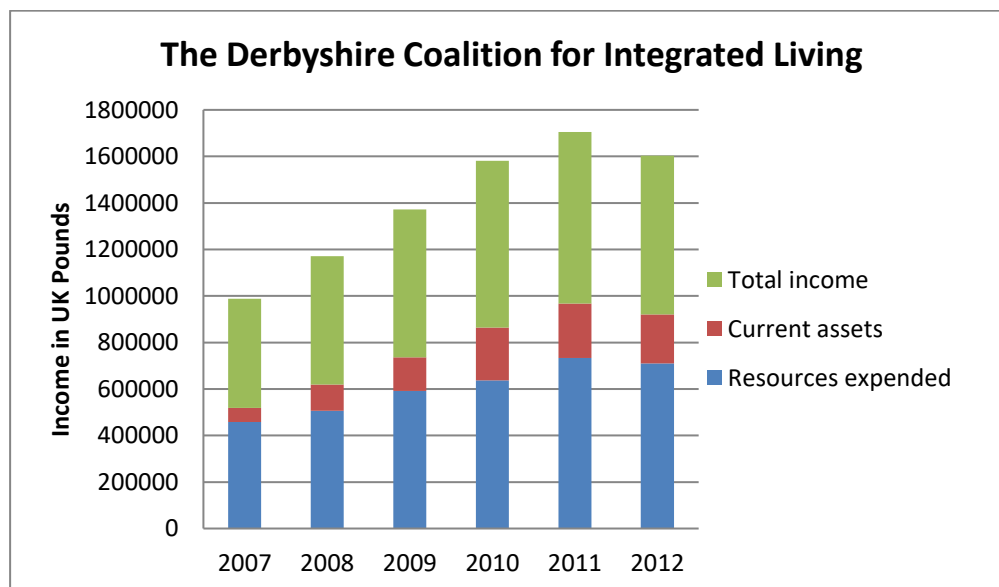


Figure 3: *Income, assets and expenditure 2007–2012: The Derbyshire Coalition for Integrated Living (Charity Commission, 2012).*

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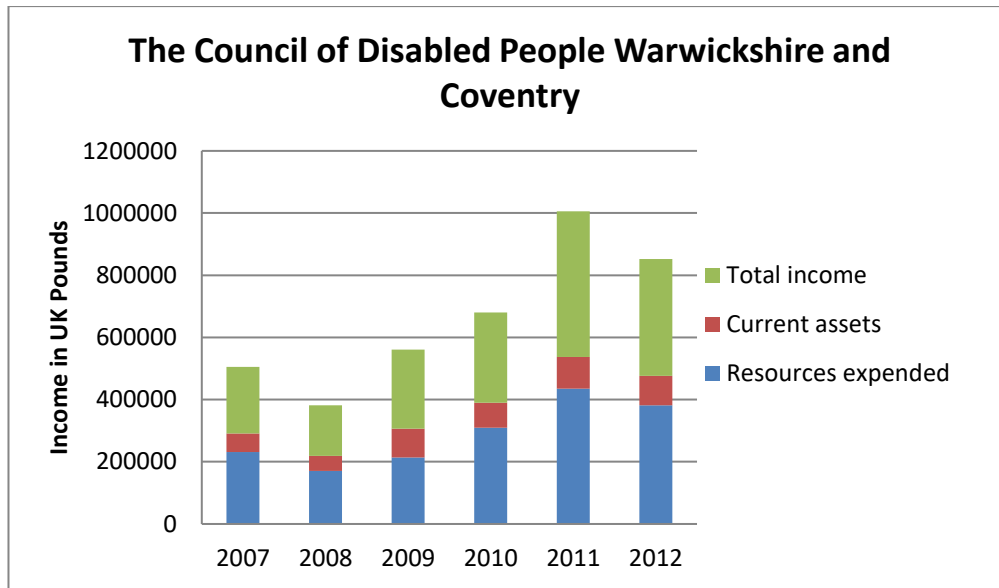


Figure 4: *Income, assets and expenditure 2007–2012: The Council of Disabled People Warwickshire and Coventry (Charity Commission, 2012).*

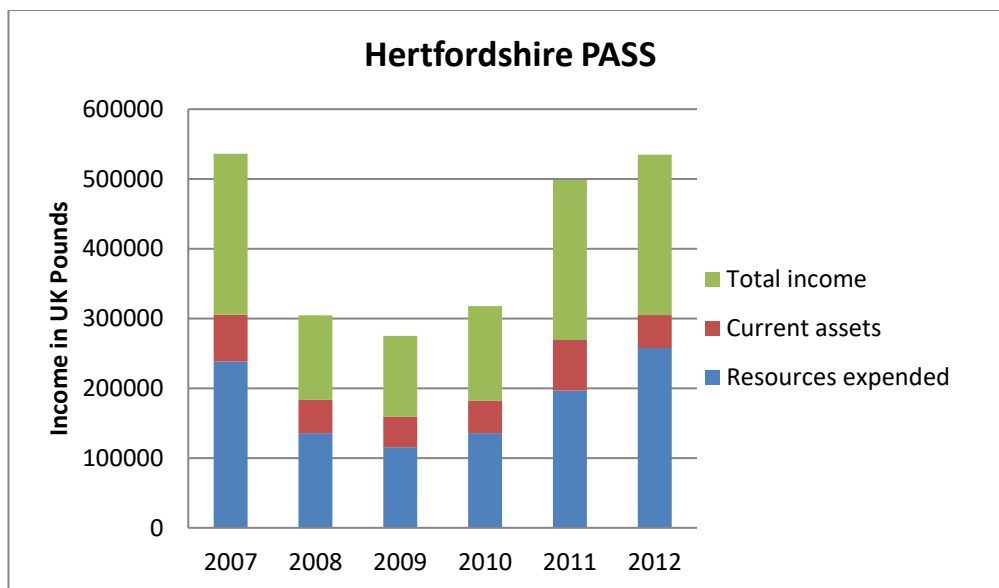


Figure 5: *Income, assets and expenditure 2007–2012: Hertfordshire PASS (Charity Commission, 2012).*

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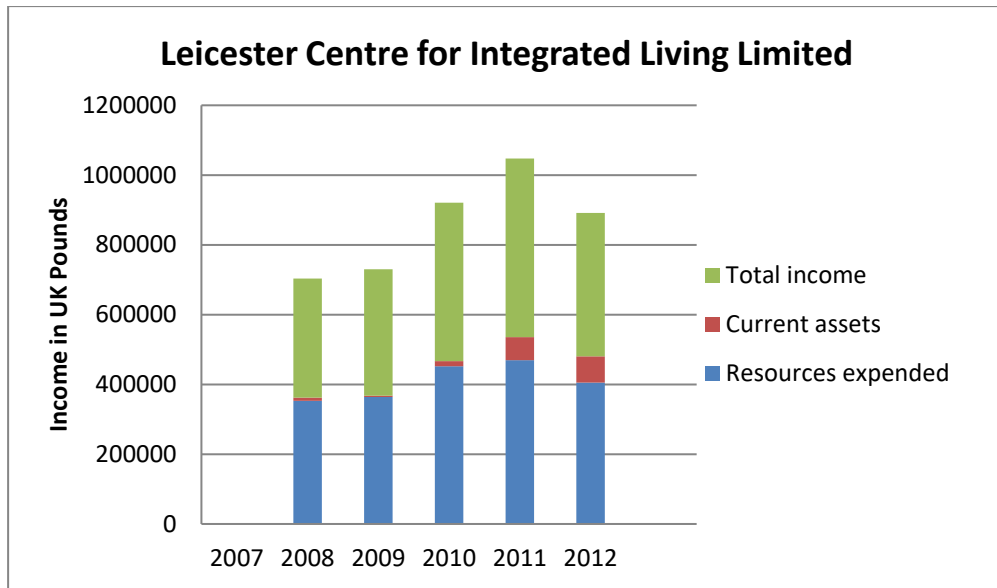


Figure 6: *Income, assets and expenditure 2007–2012: Leicester Centre for Integrated Living Limited (Charity Commission, 2012).*

As can be seen in the four bar charts above, three of the DPULOs saw reductions in total income in the period 2011 to 2012 while the other experienced a small positive increase during the same time period (Charity Commission, 2012). Table 1 shows the variation in total income for the four DPULOs for the period 2011 to 2012. The variation in total income for the four DPULOs was consistent with the findings in the Inclusion London report, which stated that 40 DDPOs surveyed had experienced funding cuts (Inclusion London, 2012).

DPULO	VARIANCE (%)
The Council of Disabled People Warwickshire and Coventry	-24.90%
Hertfordshire PASS	+0.05%
Leicester Centre for Integrated Living Ltd.	-24.59%
The Derbyshire Centre for Inclusive Living	-7.88%

Table 1: *The variation in total income for four DPULOs from outside the London area for the period 2011 to 2012 (Charity Commission, 2012).*

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The analysis of the Inclusion London (2012) report indicated that of the 54 DDPOs surveyed, some 50% indicated that their biggest funding cut was from local government sources while for 13% the biggest funding cut was from other statutory agencies. Therefore, one of the report's conclusions was that "The biggest reductions in funding came from Local Authority funding sources." (Inclusion London, 2012, p.5).

The conclusion that cuts in local government and other statutory agency funding were the source of reductions in total income for the DPULOs in table 1 was difficult to prove. This was due to the complex nature of their accounts and the way that sources of income were presented. For example, The Council for Disabled People Warwickshire and Coventry did not separate sources of income in their audited accounts (Charity Commission, 2012). Consequently, in this case, it was difficult to identify the funding that came specifically from local government and other statutory agencies. However, Leicester Centre for Integrated Living Limited. saw its funding from these sources reduced from £307,213 in 2010/11 to £172,638 in 2011/12 or a cut of 43.8%. Similarly, the Derbyshire Centre for Inclusive Living saw their revenue from these sources reduce from £399,118 to £327,330 or 18% over the same period (Charity Commission, 2012). In contrast, Hertfordshire PASS reported that total income remained flat over the same period, although resources expended increased and total assets decreased (Charity Commission, 2012). The data from these four DPULOs provided evidence that three utilised their financial reserves during the periods 2011 to 2012 to support their service provision (Charity Commission, 2012). However, the continuing use of such assets will ultimately result in the failure of an organisation and its closure (Gaskill et al., 1993). Williams (2014, p.35) agreed and claimed that '53% of 15 south-east DPULOs do not consider themselves to be financially sustainable but this is not unusual for many voluntary sector organisations in the current economic climate'. Interestingly, the issue of asset reduction was not raised in the key findings or the conclusions of the Inclusion London (2012) report.

The analyses of the Inclusion London (2012) report and the financial data from the other four DPULOs supported the claim made by Kane and Allen (2011) that the contribution from local government and other statutory agencies to the voluntary sector nationally would reduce by £2.8 billion in the 2011/16 period from a high of £12.8 billion in 2007/08.

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Grover and Piggott (2012, p.12) highlighted the problems that were faced by voluntary sector organisations during public expenditure reductions when they stated that ‘There certainly are financial challenges, particularly for those organisations that receive Government funding. This should not be a surprise, given that the Coalition Government has made it clear that the voluntary sector cannot be excluded from plans to reduce the public sector deficit.’

Bhati and Heywood (2013) reported that the Local Government Association predicted that there would be a £16.5 billion gap between funding and the cost of providing social care by 2020. This prediction appeared to be supported by the Conservative Party fiscal plan for the 2015 UK general election which stated that spending in unprotected departments (all departments, other than foreign aid, the NHS and education) would not see funding return to 2014/15 levels in real terms until after 2020 (Crawford et al., 2015). Consequently, the Local Government Association suggested that voluntary and community organisations would need to develop innovative ways for supporting local people in light of the cuts in government funding (Bhati and Heyward, 2013).

The Inclusion London (2012) report also highlighted DDPOs concerns over contract tendering, commissioning and procurement practices that might also result in the reduction of funding from local government and other statutory agencies. These concerns included: inflexible, prescriptive and time consuming tendering processes; procurement requirements that benefited large business-orientated organisations; poor tendering and procurement practice; and the bundling of smaller contracts into a single large contract (Inclusion London, 2012). The report claimed that these practices disadvantaged DDPOs when they took part in competitive tendering processes (Inclusion London, 2012).

Research undertaken by Williams (2014, p.88) on behalf of the South East Network of Disabled Peoples Organisations (SENDPO) asked local authorities and DPULOs based in the South East of England ‘Do you think that procurement rules (including European Laws) present any obstacles to commissioning DPULOs?’. The resulting report noted that 10 out of 14 local authorities surveyed thought that ‘DPULOs, especially new and emerging ones, face very real procurement challenges’ and 7 out of 15 DPULOs surveyed concurred (Williams, 2014, p.88).

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However, three out of the 15 DPULOs surveyed stated that they did not think that the procurement rules presented obstacles to DPULOs, while three did not answer either way (Williams, 2014). The report stated that ‘most of the five DPULO no obstacles respondents are based in areas where commissioners’ had ‘made significant steps to transform local authority procurement process and procedure’ (Williams, 2014, p.89).

Issues raised by the research undertaken by Williams (2014) included: the capacity of DPULOs to complete the bidding process satisfactorily; the difficulty of DPULOs competing against larger and more established organisations; DPULOs having difficulties in responding to large contracts: difficulties with cash-flow; and contracts not involving users in the evaluation of services. Williams (2014) concurred with the Inclusion London (2012) report. However, in contrast to Inclusion London (2012), Williams (2014) did not address the problems of funding cuts from local authorities or other statutory agencies.

Inclusion London (2012) also claimed that DDPOs faced an increasing risk of competition from larger disability charities and businesses during the process of contract commissioning. Williams (2014, p.35) concurred and stated that ‘some DPULOs have lost major contracts to bigger, national, non-user led providers’. Williams (2014, p.54) claimed that a contributory factor might be because the Social Value Act (2012) disadvantaged some DPULOs as ‘Under procurement regulations a tender cannot be advertised to local providers only’ although local knowledge could be an advantage. For instance, Williams (2014, p.56) identified the following key social values that Surrey County Council associated with their procurement process: ‘a strong and competitive local economy; community well-being; an engaged and resilient voluntary, community and faith sector; and innovative prevention and demand management’. However, these key social values could be fulfilled by any contractor and not only by locally based DPULOs.

One way that DPULOs might be advantaged in the commissioning process with the public sector is through Article 19 of the Public Sector Procurement Directive (2004/18/EC) (Williams, 2014). This allowed authorities to assign contracts to DPULOs that had a minimum of 50% of their workforces as disabled people.

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However, Williams (2014) noted that some DPULOs were reluctant to accept contracts under Article 19 because it restricted the flexibility of their employment practices. In addition, there was a risk that Article 19 encouraged DPULOs to use the employment of disabled people in order to obtain these contracts and thus further remove these organisations from the mainstream of society. However, some DPULOs would have still accepted contracts awarded under Article 19 as they required the funding (Williams, 2014).

In 2011, the coalition government of Conservatives and Liberal Democrats announced a new programme of funding to help strengthen DPULOs in the UK (DPULO Programme Team, 2016). The minister for disabled people, Maria Miller MP, made an additional £3 million of funding available between the years 2011/12 and 2014/15 (DPULO Programme Team, 2016). It was intended that the funding programme would be designed by DPULOs and the government (DPULO Programme Team, 2016).

The intention of the programme was to enable disabled people to 'have an equal role in society', 'play a strong role in their local communities', 'have independence in all aspects of their life', 'exercise choice and control over their lives', and 'have a strong voice' (DPULO Programme Team, 2016, p.2). The objectives were to strengthen DPULOs by enabling them to 'make their organisations more sustainable', 'be more competitive', 'deliver new services', 'operate in new sectors', 'be commissioned to provide services', and 'provide a voice for their members and service users' (DPULO Programme Team, 2016, p.2). The programme provided DPULOs with practical and financial support to develop 'Facilitation Fund projects', 'policy pilots', 'communications and PR', 'DPULO Networks' and 'capacity building' (DPULO Programme Team, 2016, p.3-4).

The programme received 382 eligible applications for funding from 264 DPULOs and the value of funds applied for was £7.32 million (DPULO Programme Team, 2016). This total was over twice the funding of £3 million that was made available by the coalition government. Consequently, 82 applications were rejected as 'there was insufficient programme funding remaining at the time the applications were made' (DPULO Programme Team, 2016, p.7). However, the DPULO Programme Team (2016, p.8) inferred that the programme was successful as '98% of all projects funded [were] completed'.

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Bott, Sweeny and Watts (2013) stated that one of the programme outcomes was as a result of research undertaken to identify the number of DPULOs in existence. Bott, Sweeny and Watts, (2013, p.5) concluded that in 2013 the ODI, through the programme, had 'details for around 340 ULOs'. Subsequently, a personal email from the communications and project officer at Shaping Our Lives (SOL) to myself stated that in 2016 there were 400 DPULOs and 52 other organisations that were not user-led on their database (Williams, 2016).

In spite of the intentions of the successive governments formed by New Labour, the coalition of Conservatives and Liberal Democrats and, in 2015, the Conservatives to support the development and strengthening of DPULOs, problems continued to exist with their viability. For example, Ivory (2008, p.24) noted that Sue Bott, the director of the NCIL claimed in 2008 that 'roughly a dozen local CILs, 15% of her membership, have closed in the past two years because they cannot afford to carry on'. The threats to DPULO survival have remained. The report by Inclusion London (2012) stated that 'one in five of the DDPOs surveyed face closure and the majority face a dramatic reduction in the range of work they provide'. Williams (2014, p.15), in research commissioned by SENDPO, questioned the success of government initiatives and noted that 'there are still many south-east local authorities which do not have thriving DPULOs'. In addition, news articles have also indicated the problems experienced by ULOs as a result of financial cuts. For example, Drake (2016, p.1) highlighted the closure of an Essex charity when she reported that 'Disability Essex provided advice, support and a place to socialise for disabled people, their families and carers since 1949 but closed this week due to financial difficulties'. Rhian Davies, chief executive of Disability Wales commented on a loss of funding when she claimed that 'Losing the core grant from the Welsh government is a devastating blow' which will mean that Disability Wales 'will have to operate very differently in future and it will unquestionably affect the amount and range of work it undertakes at a time that disabled people more than ever need a strong voice championing their rights' (ITV, 2015, p.1).

Zana Collins, CEO of the Worcestershire Association of Service Users (WASU) concluded by stating that her organisation was 'fighting to survive because of the way that councils are cutting back on ULOs' and that she was 'putting in bids left, right and centre to secure our future, but to no avail' (Ivory, 2008, p.24).

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This section has demonstrated that the UK financial crisis of 2008 resulted in a significant reduction in funding from the public sector to voluntary organisations during the period 2011 to 2016 as was predicted by Kane and Allen (2011). These reductions, arguably, forced local government to introduce a market for social care services such that, in contract provision, cost took priority over the interests of service users. This move, as reflected in the literature and my own experience of DPULOs, has resulted in increased competition between DPULOs, national charities and other organisations within the tendering process for the award of social care contracts. In addition, deficiencies have been exposed in the capability of the voluntary sector and local DPULOs to compete with larger national organisations.

For example, the senior management team at my own DPULO had to spend significantly more time and resources in preparing a contract renewal application than had been expended in the original application of three years previously. In spite of this effort the contract was awarded to a competitor that in my view did not represent the best interests of the membership of my DPULO and the other service users.

In spite of the introduction of an additional programme by the coalition government in 2011 to strengthen DPULOs - reviewed by the DPULO programme team (2016) - and evidence that has suggested that local government has been encouraged to support such organisations in the contracting process (Williams, 2014), their viability remains in question (Inclusion London, 2012; Williams, 2014).

3.7 Summary

This chapter has shown that the terminologies and definitions used to identify and categorise disabled peoples' organisations were confused and contested. Consequently, there was a risk that statistics representing such organisations were flawed. Moreover, service users who did not understand these terms might not recognise the benefits of becoming members of DPULOs while funders might not offer financial support. In addition, this chapter has demonstrated there was a lack of knowledge by successive governments concerning the numbers of DPULOs, their location and their capabilities of co-ordinating contracts for social care services.

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When these issues were recognised by the government, a number of programmes were introduced to strengthen DPULOs. Unfortunately, these programmes appear to have been seriously underfunded.

The financial crisis in 2008 and the subsequent introduction of austerity measures have also had a significant impact on the ability of DPULOs to survive and prosper. This situation has been exacerbated by reductions in social care funding which has resulted in an increase in competition between DPULOs, national charities and other organisations. This has resulted in some DPULOs struggling financially, with the risk of closure. My re-analysis of the dataset of one of the few reports to look at the impact of the economic crisis on DPULOs revealed that these organisations were facing significant funding cuts from local authorities and other statutory agencies. In addition, some DPULOs were experiencing an increase in competition from large disability charities and businesses. There were also a number of issues raised by the organisations concerning local authority contract commissioning processes, reductions in their total income and concerns about their long-term survival.

Looking across the two literature review chapters, some clear areas started to emerge for my study. For example, there were significant reductions in government funding for DPULOs, issues related to the marketisation of social care services and competition from national charities and business-oriented organisations. These challenges had an impact on service provision, particularly for the disabled clients already supported by the DPULOs. Historically, DPULOs were dependent on local authorities for financial support and did not have the skills or organisational structures to develop the business activities required to generate income in order to operate dynamic and effective organisations.

In the next chapter, I will examine the key principles in the design of a conceptual framework for this study. In addition, I will discuss the ontological and epistemological assumptions that support the methodological approach that will be taken and how these concepts result in the choice of an appropriate paradigm in which to position the research.

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CHAPTER 4: CONCEPTUAL FRAMEWORK AND METHODOLOGY

4.1 Introduction

The two literature review chapters provided a historical overview of organisations run and controlled by disabled people and explored the ways in which changes in the political, economic and policy landscape have affected the ability of disabled people's user-led organisations (DPULOs) to survive and prosper.

Initially, this chapter provides a definition of the term 'conceptual framework'.

The limitations and boundaries of the research will be discussed and a conceptual framework considered applicable to this study will then be developed.

The intention of identifying my conceptual framework was to highlight the links between the concepts and their related phenomena for the DPULOs involved in this research. Consequently, this process will support the development of the research questions and the selection of an appropriate research methodology for the study.

In addition, the chapter will examine the ontological and epistemological conventions of a range of research paradigms that will support the selection of a suitable approach for this study. The ontology, epistemology, methodology, axiology and methods employed in the chosen paradigm will then be explored.

4.2 Conceptual framework

The term 'conceptual framework' has been defined as a researcher's world view of his/her research area (Lacey, 2010). Fulton and Krainovich-Miller (2010) suggested that a conceptual framework could be described as a map for a study that provides the foundation for the development of appropriate research questions. Green (2014, p.35) pointed out that 'the framework should be there to assist the researcher to ensure that their research project has coherence and focuses their mind on what the research is trying to achieve'. Green (2014, p.36) also noted that the development of the framework in conjunction with the other elements of the methodology and the research design 'strengthens the study and gives the researcher confidence in the evidence provided by the findings'.

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The conceptual framework itself is built from a number of individual concepts where Green (2014, p.35) defined concepts as ‘symbolic statements describing phenomenon or a class of phenomena’.

For this study, I have developed a conceptual framework from a combination of the knowledge gained through my lived experience as a disabled person, as the chairman, trustee and member of a DPULO and the two literature review chapters. Table 2 below was developed to show the concepts and their related phenomena that have an impact on the operation of DPULOs.

Concepts	Phenomena
People	Trustee/Director board Chief executive officer Staff Volunteers
Competition	Other DPULOs Businesses Charities
Policy	National government Office for Disability Issues Local government
Values	Social model User-led Independent living
Income	Contracts Funding initiatives Grants
Clients	Disabled people Local government Statutory agencies
Structure	Organisational design Legal structure

Table 2: *The concepts and associated phenomena that have an impact on DPULOs.*

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The conceptual framework for this study (see figure 7 below) was developed in conjunction with table 2 to show the connections between the concepts, their related phenomena and DPULOs.

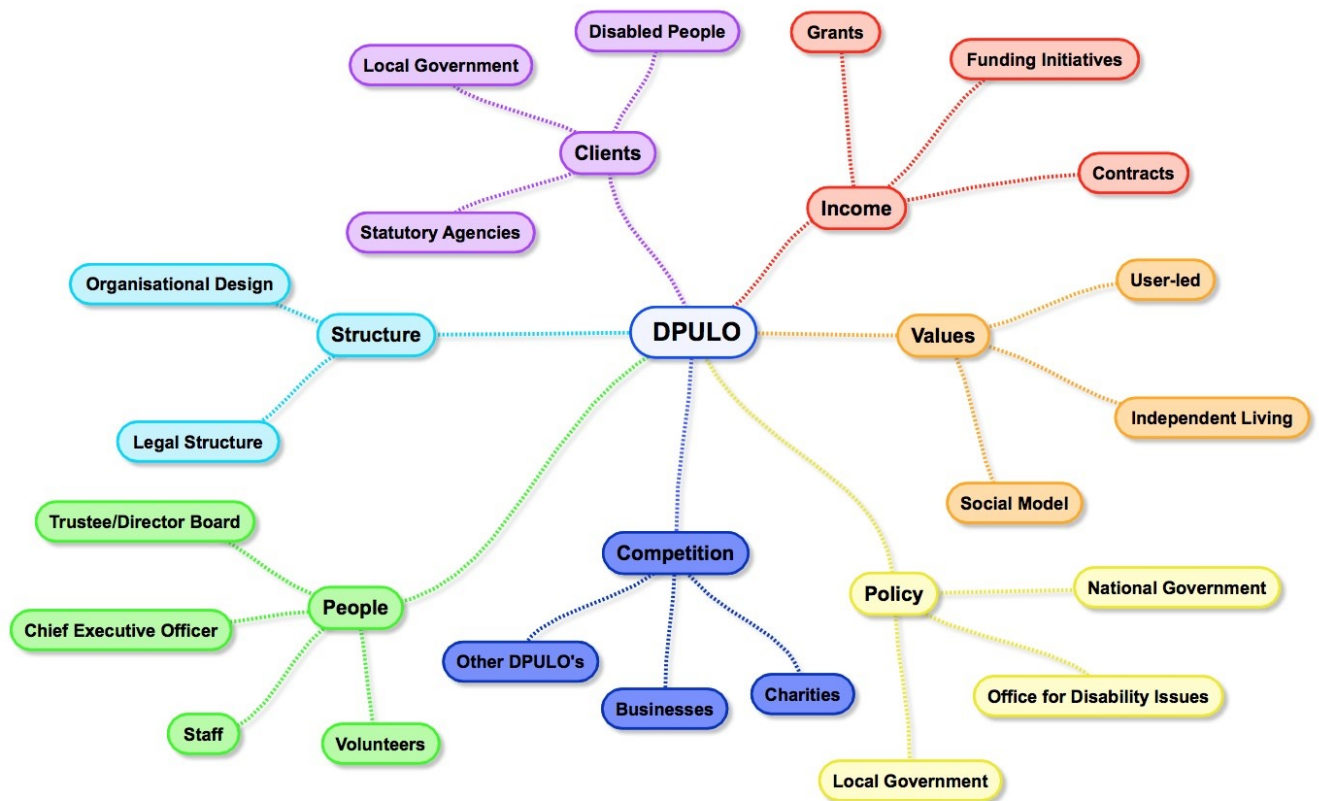


Figure 7: The conceptual framework of a DPULO for this study

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4.3 Research questions

As the chairman, a trustee and a long-term member, I had detailed knowledge about the structure, operation and future strategy of my own DPULO. Consequently, the inspiration for this thesis came from my knowledge and personal experience of disability and the issues that were being faced by my DPULO. I was interested to discover whether the challenges of maintaining and improving the services offered by my DPULO to disabled people were common to other DPULOs.

My conclusions from the two literature review chapters indicated that reductions in national and local government funding, issues related to the marketisation of social care services and competition from other more business-oriented organisations had an impact on the quality and range of services that DPULOs provided for their clients. Historically, DPULOs appeared to be dependent on local government for financial support and did not have the outlook, experience or operational structures to develop alternative methods of generating income in order to operate dynamic and effective organisations.

The research questions emerged from a combination of my experiences as a disabled person, my involvement in a number of different roles within my own DPULO, the two literature review chapters and the conceptual framework. I was particularly keen to identify the factors that might enable DPULOs to become more sustainable in the future. Consequently, my intention was that this thesis would inform the wider disability movement as well as the academic community.

The two literature review chapters indicated that research had been undertaken on the issues faced by DPULOs (see for instance: Woodin, 2006; Bott, Sweeny and Watts, 2013), but no literature was identified that specifically discussed the introduction of factors that might enable DPULOs to survive and prosper in the future. However, Blackmore & Hodgkins (2012) did suggest that DPULOs needed to develop their business and leadership skills and seek more diverse income streams.

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The research questions were developed as follows:

1. What factors influenced the establishment and development of DPULOs?
2. What are the characteristics of and current challenges for DPULOs?
3. What factors might support the future security of DPULOs?

4.4 The tools of the trade

This research study was the first that I had undertaken at such an advanced academic level and although I was familiar with the philosophical terminology used in research, such as ontology, epistemology and methodology, I was uncertain how these concepts were related to each other. In reviewing a wide range of literature on the subject, I concluded that the terminology concerned with the research design process was both confused and contested (Crotty, 1998). For example, Grix (2002, p.175) noted that 'Different academics in different disciplines attach a wide range of meanings and interpretations to the terminology of research'. However, in spite of my confusion, I was aware that as a researcher, these concepts critically influence research design, the decision making processes and the final outcome of a research study.

During my review of the literature concerned with research design, I studied in detail the paper by Grix (2002), who compared the terminology of research to a set of bricklayer's tools, with each tool having a particular function and strict order of use. Grix (2002, p.176) suggested that in research, 'specific tools have specific purposes and, if one is to employ them correctly, one must first understand what they mean, what they are meant to do and how and when to use them.' I accepted that this represented a hierarchical model that consisted of the ontology, the epistemology, the methodology and the methods appropriate to a research study (Grix, 2002). However, other authors (see for instance: Morgan, 2007; Wilson, 2008; Mertens, 2012; Biddle and Schafft, 2015) included the axiology as an additional tool in their definition of a paradigm. I defined these tools in terms of my own research study as follows:

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4.4.1 The ontology

The selection of a specific position within my research concerning the nature of reality and how it can be investigated (Crotty, 1998; Grix, 2002; Scotland, 2012).

4.4.2 The epistemology

The theory of knowledge and the potential ways of obtaining knowledge (Crotty, 1998) and the relationship between myself as a researcher and what can be known (Guba and Lincoln, 1994).

4.4.3 The methodology

The techniques employed to investigate the ontological and epistemological assumptions of my research (Guba, 1990; Scotland, 2012).

4.4.4 The axiology

The ethical principles that underpin the way that my research was conducted (Mertens, 2012).

4.4.5 The methods

The collection, analysis, and interpretation of the data that was appropriate for my study (Creswell, 2013).

These tools of research design, as I defined above, were combined to form the research paradigm for this study, where a paradigm is 'a world view, a general perspective, a way of breaking down the complexity of the real world' (Patton, 1978, p.203). However, in this study, the world view was also shaped by my previous knowledge and past experiences of the area under investigation and the academic discipline of my research (Creswell, 2012). I based the rationale for the design of my research on the hierarchical model described by Grix (2002) where the process for conducting research was defined by 'setting out clearly the relationship between what a researcher thinks can be researched (their ontological position), linking it to what we can know about it (their epistemological position) and how to go about acquiring it (their methodological approach)' (Grix, 2002, p.178). In the following section I have defined the process by which the paradigm for my research was identified.

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4.5 Building a secure foundation

Before beginning the process of identifying an appropriate research design for my study, I felt that it was necessary for me to examine the concept of a research paradigm. However, in reading a wide range of suitable literature, I concluded that the domain of research paradigms and their definitions were highly contested, and a wide range of perspectives had been proposed (see for instance: Guba and Lincoln, 1985; Guba, 1990; Tashakkori & Teddlie, 1998; Mertens, 2003).

In the course of examining the literature, I located an academic paper by Morgan and Smircich (1980) which introduced a graphical model that represented the relationship between different paradigms and the nature of their characteristics. In spite of my severe sight loss, I was able to easily visualise the concepts intended by the authors through my previous background as an electronics engineer and the skills I had perfected in the study of electronic circuit diagrams and other technical drawings.

My interpretation of the model introduced by Morgan and Smircich (1980) comprised a theoretical continuum, which encompassed subjective approaches to research on the left and objective approaches to research on the right. I then pictured the phenomenological research paradigm being located on the subjective side and the positivist research paradigm being located on the objective side. The model described by Morgan and Smircich (1980) provided me with a sense of understanding of the differences between subjective and objective research and qualitative and quantitative data.

My understanding was that quantitative research employed 'experimental methods and quantitative measures to test hypothetical generalizations' and investigated 'the measurement and analysis of causal relationships between variables' (Golafshani, 2003, p.597). Golafshani (2003) also noted that in quantitative research, data can be constructed from observable and measurable facts where the results are expressed in statistical terms through mathematical procedures. Data collection methods could include standardised tests and questionnaires, and descriptions of phenomena obtained through the use of systemised observation tools (Pring, 2000).

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In contrast, I accepted Golafshani's (2003, p.600) claim that qualitative data resulted from 'a naturalistic approach that seeks to understand phenomena in context-specific settings'. I concluded that qualitative data could be collected from, for instance, observations, textual analysis and interviews but could not be tested through statistical or similar procedures (Strauss and Corbin, 1990; Gill et al. 2008).

From my investigation of these concepts, I acquired a comprehensive understanding of the relationship between the two research paradigms within the theoretical continuum. Consequently, I concluded that the model introduced by Morgan and Smircich (1980), later discussed by Hussey and Hussey (1997) and Newman and Benz (1998), was introduced with the intention of assisting researchers in the identification of suitable designs for their research. In the following paragraphs, I offer definitions for the two research paradigms from my own interpretation of the theoretical continuum and the available literature in the area of research design.

4.5.1 Positivism

The theoretical continuum introduced by Morgan and Smircich (1980) indicated to me that the positivist research paradigm was objective in nature and was grounded in the collection of quantitative data (Mackenzie and Knipe, 2006). Consequently, positivism was also known as the scientific research paradigm, due to the empirical nature of its approach to research (Crotty, 1998) and characteristics that defined the world in terms of immutable natural laws that could be fully understood (Guba, 1990). The data collection methods I associated with positivism were scientific experimentation, computational analysis and close-ended surveys (Pring, 2000).

An example of a positivist approach to research was when, as a young science student, I learnt that a laboratory experiment undertaken under strictly controlled conditions of quantity, volume, temperature and pressure would always have the same result. I concluded that such a design produced research findings that were repeatable (Guba, 1990). In addition, as the researcher and researched were independent of each other, bias would not be introduced into the experiment (Guba, 1990).

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4.5.2 Phenomenology

The theoretical continuum introduced by Morgan and Smircich (1980) indicated to me that the phenomenological research paradigm was subjective in nature and was grounded in the collection of qualitative data (Firestone, 1987). My understanding of the purpose of phenomenological research was to identify phenomena based on the personal perceptions of an individual's lived experience, where data collection methods could include semi-structured interviews, focus groups and open-ended surveys (Lester, 1999).

My experience of phenomenological research was limited; however in 2007 I was part of a research team that conducted a study of back-to-work training for disabled people in Essex (Stevens, Carey & Edwards, 2007). This study entailed the in-depth investigation of the experiences of a small number of disabled individuals in obtaining employment after being in government-funded training-for-work. As a result, our findings were both detailed and specific, and the team concluded that the results could not be generalised (Lester, 1999).

While the two definitions I outlined above provided me with a basic conceptual model, I concluded that they represented a simplification of the range of research paradigms available (Hussey & Hussey, 1997). I came to this conclusion as a result of Guba's (1990) identification of three research paradigms that he claimed had emerged in order to challenge or replace traditional positivism. These were named by Guba (1990) as post-positivism, critical theory and constructivism. My perspective of the range of research paradigms available was further informed by Creswell (2013) who described four research paradigms: post positivism, pragmatism, constructivism, and advocacy/participatory. Subsequently, Creswell (2013), informed by Mertens (2010), redefined the advocacy/participatory research paradigm and renamed it as the transformative research paradigm.

The conclusion of my extensive investigations into these concepts enabled me to visualise where all research paradigms could be placed on the theoretical continuum as originally conceived by Morgan and Smircich (1980). However, I regarded the four research paradigms described by Creswell (2013) as representing a more contemporary perspective than that provided by earlier authors such as Guba (1990).

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Consequently, in the following paragraphs, I provided definitions for the four research paradigms from my own interpretation of the theoretical continuum as further developed by Creswell (2013) and the available literature in the area of research design.

4.5.3 Post-positivism

My perception of post-positivism was that it was located on the right-hand side of Creswell's (2013) continuum, it was objective in nature and grounded in the collection of quantitative data (Mackenzie and Knipe, 2006). Consequently, I concluded that post-positivism was similar to positivism in that it retained an empirical approach to research, used similar data collection methods, but defined the world in terms of natural laws that were not completely understood (Guba, 1990). In explaining this change of approach, Ryan (2006, p.16) emphasised that 'there is no neutral knowledge' and that 'complexity science has challenged the dominance of reductionist scientific models'. Therefore, I believed that post-positive principles were a movement towards a real-world perspective in research design where 'values and other biasing and confounding factors' were thereby not automatically excluded from the research (Guba, 1990, p.20).

An example of a study that used a post-positivist approach to research was measuring the effectiveness of a literacy development programme called Success for All in the USA (Borman et al., 2007). I believed that the post-positivist paradigm was of significance in this study as it converted human characteristics such as reading skills and financial status into numeric variables in order to analyse the research data and measure the success in teaching literacy skills in a small group of American elementary schools (Borman et al., 2007).

4.5.4 Pragmatism

My view of Creswell's (2013) continuum was that the pragmatic research paradigm was located to the left of post-positivism. I believed that the pragmatic paradigm placed the research question as central to understanding the problem that was being investigated and that a mixed-methods approach was appropriate for the collection of data (Mackenzie and Knipe, 2006).

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Creswell (2012, p.11) concurred with this view and stated that 'for the mixed methods researcher, pragmatism opens the door to multiple methods, different world views, and different assumptions, as well as different forms of data collection and analysis.'

An example of a study that used a critical, pragmatic mixed-methods approach to research was measuring the effectiveness of social work practice by collecting a mixture of quantitative and qualitative data from two drug and alcohol rehabilitation centres in Scotland (Cree, Jain & Hillen, 2014). I believed that the value of using this approach was that measuring the effectiveness of social work practice was complex and difficult to evaluate. Consequently, I believed that a mixed-methods approach that used critical evaluation techniques that provided rigorous analysis and trustworthy findings was a valid approach for this type of study (Cree, Jain & Hillen, 2014).

4.5.5 Constructivism

My observation of constructivism was that it was located on the left of pragmatism on Creswell's (2013) continuum, it was subjective in nature and grounded in the collection of qualitative data (Mackenzie and Knipe, 2006). Consequently, I concluded that constructivism was different to post-positivism in that it was interpretive in nature and used data collection methods such as semi-structured interviews, focus groups and observations (Scotland, 2012). I understood that the approach of constructivism was to identify the views of the participants in a study and that their previous experiences would influence the results (Mackenzie and Knipe, 2006).

An example of a study that used a constructivist research paradigm was an examination of the inherent political struggles within an urban housing regeneration project in London (Jacobs, 1999). The importance of a constructivist approach in this context was in the way that the researcher used qualitative interview techniques to gather opinions from agencies who were trying to shape the policy agenda (Jacobs & Manzi, 2000). The aim of the research was to analyse the nuances in the language conveyed by the main actors to identify where conflict was present and consequently, where changes were required in the existing housing policy (Jacobs & Manzi, 2000).

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4.5.6 Transformative

My opinion was that the transformative paradigm was to the left of constructivism on the continuum described by Creswell (2013), subjective in nature and could utilise a mixed methods approach to the research (Mackenzie and Knipe, 2006; Mertens, 2007, 2012). My understanding was that the transformative paradigm was a major evolutionary development of constructivism that included the agendas of power, politics and reform and had the potential to improve the lives of those involved in the research (Mertens, 2012; Creswell, 2013). In addition, Mertens (2003) clearly stated that the transformative paradigm was emancipatory in nature, with 'multiple realities that are socially constructed' but where it was 'necessary to be explicit about the social, political, cultural, economic, ethnic, racial, gender, age, and disability values that define realities' (Mertens, 2007, p.216).

An example of a study that used the transformative paradigm was an investigation of the differences between men and women in the area of social capital (Hodgkin, 2008). I understood that one of the reasons for the undertaking of this study was to investigate issues of inequality and the balance of power between men and women in sharing the benefits of social capital (Mertens, 2012). I concluded that Hodgkin (2008) concurred with Mertens' (2012, p.6) contention that in transformative research, the researcher's role is 'as a supportive, reflective activist who works to challenge the status quo' between the research participants and the society in which they live.

In the following section I have detailed the process by which I selected the research paradigm that I considered to be appropriate for my study.

4.6 The keystone of the research

Green (2014, p.34) stated that within her doctoral study the 'presence of a conceptual framework was present throughout the research project and report. It helped frame the research questions, the research design and the research outcomes'. The conceptual framework for this study was intended to respect Green's (2014) perspective (see figure 7) and shows the key concepts that were considered to influence the operation of DPULOs.

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This research was intended to determine in what way these influences affected the survival and prosperity of DPULOs. The intention was also to identify the factors that might support the future security of these organisations. Therefore, I concluded that this research was theory building rather than theory testing (Eisenhardt & Graebner, 2007). In addition, as I believed my research would be based within multiple realities (Mertens, 2007, 2012), I concluded that in the selection of a research paradigm, I should focus on the subjective portion of the theoretical continuum as described by Morgan and Smircich (1980).

Subsequently, I felt that the search for a suitable paradigm in which to position my research should consider the apparent power differences suffered by disabled people when compared to the rest of society. In addition, I wanted the chosen paradigm to support the furthering of social justice and change in DPULOs (Mertens, 2007, 2012). Consequently, I selected the transformative paradigm as the most appropriate for my research, although I was aware that it was not a perfect fit. Therefore, I could only claim that my research was informed by the transformative paradigm (Mertens, 2007; 2012).

While my selection of the transformative paradigm for this research might be contested, I concurred with Guba and Lincoln's (1989, p.83) statement that the questions raised by the use of different ontological and epistemological positions cannot be answered in an 'unambiguous and certain way or in a way that is capable of proof. The set of answers one gives is the basic belief system or paradigm'.

Earlier in this chapter, I discussed the theoretical model that Grix (2002) introduced to explain the individual components of a research paradigm, and which I then outlined in general terms for this study. Consequently, I felt that it was necessary to provide an in-depth explanation of these individual components in terms of a transformative paradigm, as follows.

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4.6.1 The ontology

The two literature review chapters indicated that disability was a socially constructed concept of which there were multiple realities (see for instance: Oliver, 1990b; Wendell, 1996; Albrecht, Seelman & Bury, 2001; Mertens, 2003; Barnes and Mercer, 2010; Birkenmaier and Berg-Weger, 2014). Mertens (2012, p.806), in discussing the transformative paradigm, stated that 'different versions of reality are given privilege over others' and that researchers must be aware of the resulting power differences. In this study, I considered that a key outcome of the research was to address the identified power differences between disabled people and society in order to influence change in DPULOs.

4.6.2 The epistemology

Within the transformative paradigm, research is undertaken through an 'interactive link between the researcher and the participants in a study' (Mertens, 2007, p.216). In this research, I considered that disability was 'located within a complex cultural context' and that 'respect for culture and awareness of power relations' was essential (Mertens, 2007, p.216). Consequently, I believed it was necessary to build relationships with members of the community in which the research was undertaken in order to investigate the nature of disability in terms of power and privilege. I felt these relationships would be achieved through the establishment of an informal dialogue between myself and the participants while the interviews were being arranged and taking place. In addition, I was confident about building a positive relationship with the participants as I was both the researcher and a member of the community being researched. However, I understood that Mertens' (2007) intention in the transformative paradigm was to empower disadvantaged groups of people to undertake research in order to improve their own lives. Therefore, as someone who was both the researcher and the researched, I would only be able to claim that my study was informed by the transformative paradigm (Mertens, 2007).

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4.6.3 The methodology

The methodology of this research was informed by my experiences as a disabled person, my involvement with a DPULO and the two literature review chapters. Therefore, my position within this study reflected Mertens' (2007, p.212) contention that the 'role of the researcher in this context is reframed as one who recognises inequalities and injustices in society and strives to challenge the status quo'. Mertens (2007, p.214) also stressed that 'the use of a single method to determine the need for social change (as in focusing a research study) can yield misleading results'. In discussing her own research, Mertens (2007, p.215) also stated that 'I collect data about the reality of human experience in such a way that I can feel confident that I have indeed captured that reality'. Within the transformative paradigm, Mertens (2007) claimed that a mixed methods approach that allowed for the collection of both qualitative and quantitative data was appropriate. Therefore, as recommended by Mertens (2007, 2012), both qualitative and quantitative data collection methods were incorporated into a two-stage sequential research design for this study. The outcomes from the analyses of both the stage 1 and the stage 2 data were brought together in the discussion and concluding chapters of this thesis.

4.6.4 The axiology

I understood the assumptions of axiology to be concerned with beliefs about the meaning of ethics of researchers in general and specifically my moral behaviour in dealing with research participants (Guba and Lincoln, 2005; Mertens, 2012). In my research, the transformative axiological assumptions were based on the contention that disability was socially constructed (see for instance: Mertens, 2003, 2007; Gilbert, 2006; Creswell, 2009) and as the two literature review chapters indicated, disabled people had experienced oppression and discrimination in many aspects of their lives (see for instance: Hunt, 1966; UPIAS, 1976; Finkelstein, 1980; Evans, 2003).

As a disabled person, I had myself experienced the effects of oppression and discrimination throughout my life. This led to me accepting the principles inherent in the social model of disability and the disabled peoples' movement. In addition, as I was the chairman, a trustee and a full member of a DPULO, I believed I was cognisant with the values and belief systems inherent in such organisations.

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Consequently, while the research was undertaken with chief executive officers (CEOs), I considered that the value of the transformative paradigm was as a tool to empower the whole constituency of DPULOs to initiate change in the social justice agenda (Mertens, 2012).

I was also conscious of the ethical implications when undertaking research with disabled people. For example, the terms of reference for ethical approval as outlined in the Anglia Ruskin University (ARU) Ethics Policy and Code of Practice for the Conduct of Research (ARU, 2014) were reflected in accounts of emancipatory disability research (Oliver, 1992; Barnes, 2004b) where the importance of cultural competency was clearly described. Mertens (2012, p.806) defined cultural competency as:

'a systematic, responsive mode of inquiry that is actively cognizant, understanding, and appreciative of the cultural context in which the research takes place; it frames and articulates the epistemology of the research endeavour, employs culturally and contextually appropriate methodology, and uses community-generated, interpretive means to arrive at the results and further use of the findings'.

4.6.5 The methods

Earlier in this chapter, I described the elements of a research paradigm. Subsequently, it became apparent to me that some authors treated the methodology and the methods as separate entities within a paradigm (see for instance: Patton, 1978; Crotty, 1998; Grix, 2002). In contrast, Mertens (2007, p.212), while discussing the transformative paradigm, included the methods as an integral part of the methodology. In explaining this position, Mertens (2007, p.216) stated that:

'a researcher can choose quantitative or qualitative or mixed methods, but there should be an interactive link between the researcher and the participants in the definition of the problem, methods should be adjusted to accommodate cultural complexity, power issues should be explicitly addressed, and issues of discrimination and oppression should be recognised'.

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I felt that my lived experience as a disabled person, my in-depth involvement in a DPULO and the measures I put in place to empower the CEOs while the semi-structured interviews and the survey were taking place fulfilled Mertens' (2007) requirements, specifically that there was a link between the researcher, the participants and the definition of the problem. However, in contrast to Mertens' (2007) discourse, I have found that maintaining a separation between the methods and the methodology has enabled me to better envisage the research process.

In stage 1 of the research, I utilised semi-structured interviews to gather insights into the perspectives of CEOs from DPULOs. In stage 2 of the research, I conducted a survey to collect data from a much wider sample of CEOs from DPULOs.

4.7 Summary

This chapter initially described how I developed a conceptual framework for the research from a combination of the knowledge gained through my lived experience as a disabled person, as the chairman, trustee and member of a DPULO and the two literature review chapters. This framework provided the foundation for the development of the research questions, the methodology and the research design for this study.

The chapter then examined the foundations, the ontological and the epistemological conventions of a range of research paradigms before describing the selection of the transformative paradigm as an appropriate approach for this study. The ontology, the epistemology, the methodology, the axiology and the methods employed in this study were then explored. It was concluded that as I was both the researcher and a member of the community that was being researched, I could only claim that my research was informed by the transformative paradigm.

In the next chapter, I will describe the data collection methods and the ethical issues inherent within this study. In addition, the appropriateness to this research of the concepts of reliability, validity, credibility, transferability, dependability and confirmability will be discussed.

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CHAPTER 5: RESEARCH METHODS

5.1 Introduction

In the previous chapter, a conceptual framework was presented from which the research questions were developed. In addition, as I was both the researcher and part of the community being researched, I could only claim that this research was informed by the transformative paradigm and that it was appropriate for this study.

This chapter describes the data collection methods and the ethical issues inherent in this study. In addition, the applicability to this research of the concepts of credibility, transferability, dependability, confirmability, reliability and validity are discussed.

5.2 A blueprint for construction - methods and process

In this section, I have described the process by which I selected the methods and the procedures for the analysis of the data.

The design of this research was based on my knowledge and personal experience of disability and my understanding of the challenges faced by disabled people's user-led organisations (DPULO)s. A number of different research designs were considered (see for instance: Creswell and Plano Clark, 2007; Maxwell, 2012; Punch, 2013) but a two-stage sequential design using a combination of qualitative and quantitative research methods was chosen. The intention was to use the findings from the stage 1 semi-structured interviews to inform the design of the stage 2 survey. Mertens (2012) confirmed that the transformative paradigm was appropriate for conducting such mixed-methods research, while a staged data collection methodology reinforced the notion of linkage between the two stages and the final outcomes of the research.

In stage 1, I used semi-structured interviews as a qualitative method of data collection in order to gain an in-depth understanding of the views of the CEOs from 12 DPULO)s. I believed that through this method and the assumptions of the transformative research paradigm, I would be able to build trusting relationships with the participants and thus with the communities that they represented.

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These relationships were established through a process of informal dialogue while the process of undertaking the research was taking place. I also considered that this method would involve the participants in the development and execution of stage 2 of the research (Mertens, 2012). In addition, it was my intention that the semi-structured interviews would help to confirm if the research questions were appropriate for this study.

In stage 2, I used a survey that was intended to collect quantitative and qualitative data in order to extend the depth and understanding of the outcomes from stage 1 by increasing the number of participants involved in the research. This would enhance the knowledge gained during stage 1 and encourage a dialogue with a wider range of participants. In addition, I felt that this would improve the credibility of the study with both the community and scholars (Mertens, 2007). This transformative mixed-methods approach focused on the identification of those areas of importance to the participants that might stimulate change in DPULOs. It was intended that the knowledge that emerged from the study would be used to identify the factors that might support the future security of DPULOs.

In the following sections, I have outlined the processes by which I undertook the stages of research.

5.2.1 Stage 1 - Semi-structured interviews

As a full member, long-term trustee and former chairman, I had detailed knowledge about the operation of my own DPULO. However, this research required me to obtain comprehensive insights into the operation of a variety of similar organisations. Gill et al. (2008, p.291) claimed that such insights could be investigated through a number of methods including 'observation, textual or visual analysis' but that one of the most common methods used was interviews. Gill et al. (2008, p.292) also suggested that 'the purpose of the research interview is to explore the views, experiences, beliefs and/or motivations of individuals on specific matters' and is 'particularly appropriate for exploring sensitive issues'. For instance, in the case of DPULOs, I considered these to include confidential financial and personal data, future strategic plans and business relationships. DiCicco-Bloom and Crabtree (2006) and Gill et al. (2008) described the semi-structured interview as a set of prearranged open-ended questions that allow the interviewer or interviewee to pursue an idea or response in greater depth.

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As a result, I concluded that the most appropriate method of data collection for this stage of the research was through semi-structured interviews.

The interview questions for stage 1 were chosen as a result of my personal experiences as a disabled person, involvement with my own DPULO, the two literature review chapters and the research questions. The interview questions were directly linked to the following themes: historical roots; structures and characteristics; key challenges; and future opportunities. Creswell (2013, p.190) suggested that qualitative interviews should consist of 'generally open-ended questions that are few in number.' In addition, DiCicco-Bloom and Crabtree (2006, p.316) were more precise when they claimed that 'The basic research question may well serve as the first interview question but between 5 and 10 more specific questions are usually developed to delve more deeply into different aspects of the research issue.' Gill et al. (2008, p.292) claimed that the semi-structured interview is useful in this respect 'as it provides participants with some guidance on what to talk about, which many find helpful. The flexibility of this approach, particularly compared to structured interviews, also allows for the discovery or the elaboration of information that is important to participants but may not previously been thought of as pertinent by the research team.' Therefore, I designed six main interview questions and some additional prompts to encourage the participants to consider the questions further.

Turner (2010, p.755) recommended that 'A pilot test should be conducted with participants that have similar interests as those that will participate in the implemented study.' Gill et al. (2008, p.293) stated that it was sensible to test the validity of an interview schedule because 'This allows the research team to establish if the schedule is clear, understandable and capable of answering the research questions, and if, therefore, any changes to the interview schedule are required.' Turner (2010, p.755) pointed out that 'The pilot test will assist the researcher in determining if there are flaws, limitations, or other weaknesses within the interview design and will allow him or her to make necessary revisions prior to the implementation of the study.' I undertook an informal pilot study that was intended to evaluate the suitability of the research questions and examine the cogency of the interview schedule. This was carried out with my two supervisors, my personal assistant and an acquaintance who had previously run a user-led organisation (ULO) and consequently had an understanding of the concept and operation of DPULOs.

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During the pilot, all but one of the interview questions triggered a full and frank discussion. However, the participants considered that question 4 was confusing and that further explanation was required in order to offer a clear and relevant response. Therefore, I made two changes to the schedule by redesigning question 4 and adding an additional prompt to encourage participants to further reflect on their answers. I then undertook another pilot study to test the revised question and prompt. These were regarded as suitable replacements in the interview schedule. The key areas that the interview questions covered were: general information concerning the history, structure, values and operation of DPULOs; the challenges faced by the participant in terms of their DPULO; the perspective that the participant placed on professionalism in their DPULO; the perspective that the participant held concerning the importance of professionalism to the stakeholders of their DPULO; the future opportunities suggested by the participant in terms of their DPULO; and anything else the participant wanted to say about their DPULO. The revised schedule is shown in appendix 1.

After confirming the interview schedule for stage 1, I was ready to begin recruiting participants. I have outlined the recruitment process in the following section.

5.2.1.1 Stage 1 - Participant recruitment

The first stage of the process was to establish the sampling frame for CEOs of DPULOs. As discussed earlier in this chapter, the definition of a DPULO was first proposed by the Office for Disability Issues (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). For the purposes of this study, I used this definition because DPULOs were run and controlled by disabled people and had a minimum of 75% of disabled people on their board; DPULOs actively demonstrated a commitment to employing disabled staff and volunteers; and DPULOs actively demonstrated a commitment to the principles embraced in the social model of disability (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). However, I also noted that Turnbull (2012) pointed out that this definition was extended by the ODI to include those organisations that were actively working towards achieving these objectives.

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I conducted a search of internet websites and the Shaping Our Lives User Network Membership Database (SOL, 2014) to identify organisations that displayed the characteristics of DPULOs as defined by the ODI (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). Creswell (2013, p.120) suggested that in social research, it was necessary to identify 'individuals who are accessible, willing to provide information, and distinctive for their accomplishments' and can 'shed light on a specific phenomenon or issue being explored.' Therefore, the individuals that I approached for stage 1 were CEOs from DPULOs that operated in the UK. I believed that this approach would allow for an analysis of the building of organisational knowledge and experience, and the nature of change in DPULOs over time.

Kaiser (2009, p.1,634) noted that 'confidentiality is addressed during data cleaning. Researchers remove identifiers to create a 'clean' data set. A clean data set does not contain information that identifies respondents, such as a name or addresses' and that 'some identifiers are easily recognised and dealt with. For example, the names of respondents can be replaced with pseudonyms.' I placed each of the DPULOs into one of three groups related to the date in which they were established, and the CEOs were identified by unique numbers. My intention was to safeguard the anonymity of the CEOs and organisations taking part. Randomly selected pseudonyms were allocated to the three DPULO groups as follows: "M", DPULOs established prior to 1990; "E", DPULOs established 1990 to 1999 inclusive; and "F", DPULOs established after 1999. These three categories were used as I believed that such a structure would enable me to recruit CEOs from DPULOs established across all the dates outlined in the two literature review chapters and up until the stage 1 interviews took place. In addition, I realised that from my personal experience, there were differences between DPULOs depending on their date of establishment, and the choice of these three categories would enable me to further investigate this belief.

In the next section, I will explain the recruitment process for stage 1 of the research.

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5.2.1.2 Stage 1 - The recruitment process

In order to identify a suitable sample of participants for stage 1 of my research, I used an accepted method for the selection of my research participants. This was known as purposeful sampling. DiCicco and Crabtree (2006) suggested that interview participants should be selected through a process of purposeful sampling that is aimed at maximising the depth and richness of the data necessary to investigate the research questions. Hussey and Hussey (1997) stated that qualitative research did not require a particularly large number of participants to obtain a rich set of data. Sandelowski (1995, p.183) agreed but added that:

‘an adequate sample size in qualitative research is one that permits – by virtue of not being too large – the deep, case-orientated analysis that is a hallmark of all quantitative enquiry, and that – by virtue of not being too small – a new and richly textured understanding of experience.’

Therefore, I considered that a minimum of three participants in each of the “M”, “E” and “F” categories was an adequate number to satisfy the dilemma presented by Sandelowski (1995). Eighteen CEOs of DPULOs, located in all four countries of the UK, were contacted by email in two groups of nine. The first group of CEOs were given two weeks to reply to the initial email after which, if necessary, a further email was sent as a reminder. I then gave a final period of two weeks for the CEOs to reply. From this first group, seven CEOs agreed to take part, one declined and one did not respond. I monitored the responses to ensure that CEOs from each of the three categories were enrolling in the study. This process was then repeated with the second group. From the second group, five CEOs agreed to take part, two declined and two did not respond. The result of this process was that a minimum of three CEOs from each category were successfully recruited. I then deleted the names and contact details from the research databases of those who had decided not to take part or failed to respond to my email communications.

Burnard (2004) recommended that standard conventions for identifying participants should be incorporated into the research design. Consequently, I adhered to Burnard’s (2004) recommendations as follows:

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1. I positioned the CEOs who agreed to take part in one of the “M”, “E” or “F” categories contingent with the date in which their organisation was established as previously explained, In the course of undertaking my literature review (chapters 2 and 3), I was unable to locate any terms that directly referred to the three categories of DPULOs involved in my stage 1 semi-structured interviews. However, in selecting suitable pseudonyms for the three categories, I felt it was important to choose terms that were relevant to the time periods in which they were established, reflecting the issues identified in the two literature review chapters and compared with the period in which I undertook my interviews. Consequently, I selected pseudonyms such that: Mature described DPULOs established prior to 1990; Established described DPULOs established 1990 to 1999 inclusive; and Fledgling described DPULOs established after 1999;

2. Eleven of the DPULOs had been established on dates that were consistent with the “M”, “E” and “F” categories. M2 had been established in 1975 and so fell outside these categories, but I chose to include it in the “M” category because in the 1980s it was taken over by disabled people and became a DPULO. Consequently, I positioned three CEOs in the “M” category, five CEOs in the “E” category and four CEOs in the “F” category;

3. I assigned the CEOs into each of the three categories using unique numerical identifiers in ascending order beginning with the number “1” so that the “M” category used the pseudonyms “M1” to “M3”, the “E” category the pseudonyms “E1” to “E5” and the “F” category the pseudonyms “F1” to “F4” inclusive. The use of pseudonyms thereby ensured that the anonymity of the CEOs was maintained in accordance with the conditions of the Anglia Ruskin University (ARU) research ethics regulations (ARU, 2015);

4. As far as possible, my intention was to recruit CEOs from DPULOs that were located across the UK (see table 3).

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DPULO PSEUDONYM	DATE ESTABLISHED	PHYSICAL LOCATION
M1	1981	LONDON
M2	1975 (1980s)	LONDON
M3	1985	NORTH WEST
E1	1997	SOUTH WEST
E2	1995	WEST MIDLANDS
E3	1995	SOUTH EAST
E4	1997	NORTH EAST
E5	1992	NORTH WEST
F1	2005	SOUTH EAST
F2	2000	SOUTH WEST
F3	2007	SOUTH WEST
F4	2009	NORTH WEST

Table 3: *Pseudonyms, date established and physical locations for the 12 DPULOs who took part in the stage 1 research.*

The location in the UK of each organisation was confirmed during the initial contact with the CEOs and through other sources including the internet. This process demonstrated that organisations from all areas of England contributed to this stage of the research. However, no CEOs from organisations located in Scotland, Wales or Northern Ireland responded to the initial requests to take part. These countries of the UK have significantly smaller populations than England and, therefore, smaller numbers of disabled peoples' organisations and I was unable to recruit any CEOs from these countries.

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I had attached a letter of introduction, a participant information sheet and a consent/withdrawal form to each email (see for instance: Hussey and Hussey, 1997; Crotty, 1998; Creswell, 2013). A copy of the letter of introduction, participant information sheet and consent/withdrawal form are shown in appendix 2.

Gill et al. (2008, p.292) suggested that 'Before an interview takes place, respondents should be informed about the study details and given assurance about ethical principles, such as anonymity and confidentiality. This gives respondents some idea of what to expect from the interview, increases the likelihood of honesty and is also a fundamental aspect of the informed consent process.' These details were contained in the letter of introduction and participant information sheet I sent to the CEOs who were asked to participate in my research. I then contacted the CEOs who had agreed to take part in order to informally introduce myself, discuss the study in more detail, confirm that they supported my identification of the research problem and make the necessary arrangements for the interviews to take place.

In the next section, I will describe the process of collecting data through the use of the semi-structured interviews.

5.2.1.3 Stage 1 - The data collection process

In stage 1 of my research, I had to consider whether face-to-face or telephone interviews were most appropriate for collecting the data. Sturges and Hanrahan (2004, p.108) stated that 'Qualitative researchers generally rely on face-to-face interviewing when conducting semi-structured and in-depth interviews.' In describing the benefits of this technique, Knox and Burkard (2009, p.567) suggested that they 'allow the observation not only of verbal but also nonverbal data. When in the same room, for instance, participant and interviewer have access to facial expressions, gestures, and other paraverbal communications which may enrich the meaning of the spoken words.' However, this aspect of the face-to-face interview presented me with an overwhelming challenge. A major disadvantage to myself as a blind researcher is the absence of visual cues which are known to improve the value of qualitative data.

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As Knox and Burkard (2009, p.567) noted: 'one assertion frequently made in support of in-person interviews is because both researcher and participant are in the same space, and thus have access to more than just verbal data, they can build the rapport that may enable participants to freely disclose their experiences more effectively'.

However, Knox and Burkard (2009, p.568) cautioned against the exclusive use of face-to-face interviews and suggested that telephone interviews were a sensible alternative in that 'they enable researchers to include participants from virtually any geographic region; no one is required to travel for the interview. The ability to cast this broader net is quite attractive to researchers who seek an efficient and economical way to capture the experiences of nonlocal participants.' In addition, Opdenakker (2006, p.2) suggested that telephone interviews enabled the researcher 'to contact populations that might be difficult to work with' including, for instance people with disabilities. An issue of significant importance for some disabled researchers is the challenge of travelling long distances by public transport or having to rely on a personal assistant for support. Thus, a significant benefit of the telephone interview technique for me as a blind researcher is that I do not have to travel to carry out my research. However Knox and Burkard (2009, p.570) claimed that the telephone interview does not 'clarify the information being communicated' and this is a distinct disadvantage for 'those with hearing difficulties or those whom English is not their first language'. Knox and Burkard (2009, p.470) suggested that such people 'may encounter fewer difficulties in face-to-face interviews'. Although Knox and Burkard (2009, p.470) also stated that 'researchers may want to consider both financial and time resources as well as participant accessibility' and 'where feasible, perhaps participants could be permitted to choose how their interview is conducted, in the hope that they would be more forthcoming in the approach with which they were most comfortable.' In a study which compared telephone with face-to-face interviewing, Sturges and Hanrahan (2004, p.107) concluded that 'Comparison of the interview transcripts revealed no significant differences in the interview data' and as a consequence 'telephone interviews can be used successfully in qualitative research.' Therefore, I selected a mix of both face-to-face and telephone interviews for this stage of the research.

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Turner (2010, p.754) introduced the concept of an interview protocol as one of 'the effective ways to conduct in-depth, qualitative interviews'. Boyce and Neale (2006, p.5) claimed that interview protocols are 'the rules that guide the administration and implementation of the interviews. Put simply, these are the instructions that are followed for each interview, to ensure consistency between interviews, and thus increase the reliability of the findings.' Jacob and Furgerson (2012, p.1) stated that 'An interview protocol is more than a list of interview questions; it also extends to the procedural level of interviewing and includes a script of what you will say before the interview, script for what you will say at the conclusion of the interview, prompts for the interviewer to collect informed consent, and prompts to remind the interviewer the information that she or he is interested in collecting.' Turner (2010, p.754) described this as 'creating a step-by-step process for implementation.' Jacob and Furgerson (2012, p.9) concluded by suggesting that 'A good interview protocol is essential to getting the best information from the participants in your study.' Therefore, I added a protocol to the existing interview schedule to create a standardised formal procedure that I could follow with my participants in both the face-to-face and telephone interviews. The interview protocol I designed for use in the stage 1 research is shown in appendix 1.

Tessier (2012, p.447) referred to the main methods of recording data from qualitative research interviews and suggested that 'When conducting an interview, choices on how to "record" the data have to be made. One can decide to use field notes only, use a recording device or both.' However, Opdenakker (2006, p.2) claimed that 'Taking notes during the interview is important for the interviewer; even if the interview is tape recorded [just] in case of malfunctioning of the tape recorder'. As a blind researcher, the taking of notes or writing with a pen is difficult due to problems with hand\eye co-ordination. Therefore, I decided not to take field notes and instead chose an accessible digital recorder to record my interviews. I recorded the face-to-face interviews with a cardioid microphone and the telephone interviews with an Olympus TP7 earpiece. This resulted in high quality digital audio recordings that I transcribed into Microsoft Word documents with the use of a professional transcription application called Express Scribe. As noted by Gale et al. (2013, p.4) the 'process of transcription is a good opportunity to become immersed in the data and is to be strongly encouraged.'

In the next section, I have discussed the process by which I analysed the data that was collected from the stage 1 semi-structured interviews.

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5.2.1.4 Stage 1 - The interview analysis

The analytical approach I used to interpret the interviews from this stage of the research was that of thematic content analysis (Burnard et al., 2008). I began the process by reading each transcript and identifying words, phrases and sentences that I considered to be of relevance to the research questions. I then placed these in a table by interview question and DPULO/CEO identifiers. Interviews can be analysed by software such as NVivo (NVivo, 2010). However, as a blind researcher who exclusively relies on a screen reader to access computers, I found the use of software such as NVivo (NVivo, 2010) to be somewhat inaccessible. Therefore, I felt that the manual method as described by Burnard et al. (2008) provided me with a recognised starting point for the analysis of my interview transcripts.

This stage of the analysis was checked by another researcher who reviewed the transcripts independently to discern the key issues and processes (Munn-Giddings, 2002). These were compared and it was confirmed that my analysis was appropriate. Gale et al. (2013, p.4) suggested that the researcher then used a data coding process with codes and categories to 'classify all of the data so that it can be compared systematically with other parts of the data set.' Gale et al. (2013, p.2) defined a code as a 'descriptive or conceptual label that is assigned to excerpts of raw data' and recommended that codes were placed in categories in order to manage and organise the data.

However, as a blind researcher, I was unable to undertake the process of assigning conceptual labels to my data as this process was inaccessible to me. Therefore, I designed a modified version of the method described by Gale et al. (2013).

This process involved comparing the words, phrases and sentences contained in each of the DPULO/CEO identifiers with their respective transcript so that selected quotations could be placed directly into categories without applying codes. I repeated this process for all the other transcripts but added additional categories where necessary (DiCicco-Bloom and Crabtree, 2006). I then reviewed each quotation to ensure that they were in the most appropriate category.

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Finally, I compared and contrasted the categories and merged categories where appropriate to generate a theoretical framework that represented both the research questions and the overarching themes of the study as follows: historical roots; structures and characteristics; key challenges; and the future opportunities for DPULOs (Glaser and Strauss, 1967; Gale et al., 2013).

However, while my modified design for the coding process described by Gale et al. (2013) was preferable to attempting to use software such as NVivo (NVivo, 2010), I still experienced significant challenges with the identification of relevant data for the analysis of the stage 1 research.

The key challenge I faced during this process was access to the 12 semi-structured interview transcripts. In total, the 12 transcripts amounted to 280 A4 pages that contained approximately 125,000 words. The 12 transcripts were appraised several times in order to select the required quotations for each of the categories. However, as the user of a screen reader, I had to carefully listen to the individual words contained within the 12 transcripts in order to be confident that I had captured the relevant quotations for each of the identified categories. In addition, the resulting quotations amounted to 104 A4 pages. Therefore, the process was extremely time-consuming and the quotations eventually became difficult to handle as I required a high level of concentration for long periods of time in order to successfully complete the required analysis. The entire process took me eight months to complete. However, I felt that the focus I managed to achieve in employing the screen reader application enabled me to successfully accomplish the task of analysing the data within the 12 transcripts and to select the most appropriate quotations for inclusion in chapter 6. The findings from this stage of the research were used in the design of the stage 2 survey as described in the following sections.

5.2.2 Stage 2 - Survey

In this study, the stage 1 findings were used to inform the design of the stage 2 survey. While there is a growing body of literature related to the definition and use of mixed methods (see for instance: Tashakkori and Teddlie, 1998; Driscoll et al., 2007; Creswell and Plano Clark, 2007), I am locating this study in Mertens' (2012) notion of mixed methods which I understand to mean the use of complementary methods, appropriate to the research question, to illuminate the issue under study.

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I am aware that some authors might rather see my design as a sequential, two-stage design or indeed multi-method. The stage 1 research explored in depth the issues that CEOs found most pertinent in relation to their DPULOs. This gave me very rich data and many qualitative researchers would find that sufficient. However, because of the nature of the research and my quest (as befitting the transformative paradigm to ensure results that would have a practical as well as philosophical meaning), I chose a method that would explore whether or not my core findings in stage 1 had a wider meaning in the DPULO community. Therefore, the core findings from the stage 1 research informed a wider survey to the DPULOs across the UK. The discussion chapter draws across both sets of data and discusses both the similarities and differences in the responses.

According to Driscoll et al. (2007, p.21) sequential mixed methods data collection strategies enabled the collection of data 'in an iterative process whereby the data collected in one phase contribute to the data in the next.' Consequently, the findings identified as a result of the analysis of the stage 1 data were used in the development of a survey used in stage 2. Driscoll et al. (2007, p.21), in discussing the work of Creswell and Plano Clark (2007), also suggested that such methods allowed for the access to 'participants who can best provide that data' and 'by verifying and augmenting study results from members of a defined population.' Therefore, the intention of this stage of the research was to gather both qualitative and quantitative data by undertaking a survey of the population of CEOs of DPULOs. As recommended by Mertens (2007), this was undertaken in order to obtain insights from the CEOs and to demonstrate the credibility of the research.

In the next section, I have explained the process by which I selected the participants for the survey.

5.2.2.1 Stage 2 - Participant recruitment

The method I used to gain access to a database of DPULOs and therefore the contact details and names of CEOs from DPULOs in the UK was initiated through discussions with a gatekeeper. Saunders (2006, p.126) defined a gatekeeper as 'The person who controls research access. For example, the top manager or senior executive in an organization, or the person within a group or community who makes the final decision as to whether to allow the researcher access to undertake the research.'

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In discussing research in the health care arena, Lee (2005, p.23) claimed that the purpose of a gatekeeper was to 'ensure that vulnerable people such as patients and their families are protected'. However, in the opinion of both myself and the gatekeeper, the views expressed by Lee (2005) were not valid in this research, because in light of their age, position and level of responsibility, we did not believe that the CEOs of DPULOs could be considered to be vulnerable. The reasons I chose to engage a gatekeeper were: to maintain my ethical integrity by not having direct access to participants; to maximise research response rates by choosing a gatekeeper with a high level of professional credibility with CEOs of DPULOs; and, as a blind researcher, I required a simple and efficient method of gaining access to the defined population of participants in my study.

I identified a senior executive from within the ODI Strengthening DPULOs Programme (DPULO Programme Team, 2016) to act as an appropriate potential gatekeeper. As part of my initial communication, I explained the purpose of the research, and supplied an electronic copy of the participant letter and a draft facsimile of the survey as evidence of my plans to engage with CEOs of DPULOs (Lee, 2005). After considering my approach, the ODI senior executive agreed to act as the stage 2 gatekeeper. In addition, as the representative of the CEOs listed on the ODI's database of DPULOs, the senior executive confirmed that he/she agreed with my identification of the research problem. In the next section, I will describe the method I used to collect data in the survey.

5.2.2.2 Stage 2 - The data collection process

In discussing the benefits of conducting survey pilot studies, van Teijlingen and Hundley (2001, p.1) claimed that 'the wording and the order of the questions, or the range of answers on multiple-choice questions, might be piloted' to 'give advance warning about where the main research project could fail, where research protocols may not be followed, or whether proposed methods or instruments are inappropriate.' I undertook an informal pilot study of the draft survey with my two supervisors, my personal assistant and the ODI senior executive to evaluate the suitability of the questions and its overall structure. As a result, a number of minor semantic and structural changes were incorporated into the draft survey. The revised survey was sent back to my two supervisors, my personal assistant and the ODI senior executive for further evaluation. On this occasion, they all found my survey to be suitable for use in the study.

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I believe this evaluation was particularly significant in terms of the senior executive as he/she was the representative of the CEOs included in the ODI's database of DPULOs.

Jones et al. (2008, p.67) claimed that the use of an online questionnaire was an advantage because 'respondents can be guided through the process to ensure they complete the questionnaire fully, properly and in the correct order' and where the data analysis tools were an 'integral part of the web site.' Therefore, the finalised survey was placed in an online response tool called SurveyMonkey (SurveyMonkey Inc., 2018).

There were two key reasons for my selection of the online response tool SurveyMonkey (SurveyMonkey Inc., 2018) to undertake my stage 2 research. Firstly, I previously used SurveyMonkey (SurveyMonkey Inc., 2018) in a study (see: Carey et al., 2013). While I discovered that this online survey response tool was not fully accessible, I felt that it would enable me to fulfil the required aims of stage 2 of my research without having to investigate other similar software applications. Secondly, at the time I was designing my draft survey, Survey Monkey (SurveyMonkey Inc., 2018) was a recognised online response tool at ARU and was freely available for staff and students to undertake research.

The main advantage for me as a blind researcher in using SurveyMonkey (SurveyMonkey Inc., 2018) was in the design phase of my stage 2 survey. I was already aware that the design tools within SurveyMonkey (SurveyMonkey Inc., 2018) were fully accessible in terms of my screen reader software. Consequently, I was able to produce an online survey that provided the participants with an intuitive method of responding to my stage 2 questions (Jones et al., 2008).

Subsequently, the gatekeeper sent a personal introduction, the participant letter and an internet link to the survey to the members of the ODI Strengthening DPULOs Programme database of 340 DPULOs (n=340) (see: Bott, Sweeny and Watts, 2013). A copy of the personal introduction from the ODI senior executive and my participant letter are shown in appendix 3. The personal introduction from the ODI senior executive and my participant letter both stressed that the survey should only be completed by the CEO of the DPULO to which the request had been sent. Included in the participant letter was a firm cut-off date by which the survey had to be completed. A copy of the finalised survey is shown in appendix 4.

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However, I was aware that the SurveyMonkey (SurveyMonkey Inc., 2018) data analysis tools were not fully accessible to screen readers. Therefore, this resulted in two main problems for me as a blind researcher. Firstly, the participant responses were presented in both graphical and tabulated formats. The graphical content confused my screen reader and resulted in the document being difficult to access. Secondly, the participant responses were presented in a PDF format. This resulted in the cursor on my computer being placed at the beginning of the PDF every time I switched to another document, creating further confusion. As a consequence, I required a significant level of assistance from my Disabled Student Allowance (DSA) support worker in order to access the data in the PDF document. However, in spite of these access issues, I felt that SurveyMonkey (SurveyMonkey Inc., 2018) provided me with a familiar online response tool that enabled me to undertake the data analysis required to complete the two stages of my research. In the next section, I will describe the data analysis stage of the survey.

5.2.2.3 Stage 2 - The data analysis process

Following the closure of the survey, the returns were automatically analysed by the SurveyMonkey (SurveyMonkey Inc., 2018) tools, and separate sets of results were produced for the qualitative and quantitative data.

The analysis of the participant responses produced summary data presented in percentages, response counts and open-ended answers (Pring, 2000; Golafshami, 2003; Creswell, 2012; SurveyMonkey Inc., 2018). This summary data enabled me to undertake the required narrative analysis that was appropriate for this research (The University of Reading, 2001; SurveyMonkey Inc., 2018). Allen (2017, p.44) stated that 'Narrative analysis is a genre of analytic frames whereby researchers interpret stories that are told within the context of research and/or are shared in everyday life. Scholars who conduct this type of analysis make diverse—yet equally substantial and meaningful—interpretations and conclusions by focusing on different elements.' In addition, Allen (2017, p.44) pointed out that 'scholars from a variety of perspectives ranging from quantitative to qualitative as well as traditional to postmodern conduct narrative analyses, which makes it challenging to cover all of its nuances; however, broad strokes are possible.' In the case of my own research, I interpreted the data from the stage 2 survey in such a way that I was able to compare and contrast the outcomes with the stage 1 semi-structured interviews and my lived experience as a disabled person; my knowledge as a trustee of a DPULO;

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and my full membership of a DPULO (Allen, 2017). This process allowed me to identify the similarities and differences between the two stages of research (Driscoll et al., 2007; Creswell and Plano Clark, 2007; Creswell, 2012). Consequently, by using a narrative analysis to interpret the data, I was able to link the outcomes of the semi-structured interviews and survey to my lived experience as a disabled person in order to demonstrate the credibility of my overall study (Mertens, 2007). In summary therefore this approach enabled me to complete the cycle so that the findings from the stage 1 semi-structured interviews informed the design of the stage 2 survey. In turn, the findings from the stage 2 survey were compared and contrasted with the findings from the stage 1 semi-structured interviews in order to discern the similarities and differences between the two stages of my research (Driscoll et al., 2007; Creswell and Plano Clark, 2007; Creswell, 2012).

One of the questions in the stage 2 survey (see chapter 7, question 6) was designed to provide only qualitative data. The CEOs were asked to identify two key values that they believed were important to their organisations. However, they were not required to prioritise their responses. Of the 133 CEOs that responded to the survey, 122 provided a response for Value 1, 120 provided a response for Value 2, and 11 gave no answer.

The initial stage of the process was to combine the Value 1 and Value 2 responses. A process of thematic content analysis (Burnard et al., 2008) was then undertaken so that responses considered to be similar were identified (Strauss and Corbin, 1990). Those responses considered to be similar were placed in appropriately named categories, where category names were derived from: Question 6 responses; the two literature review chapters; the stage 1 research; my lived experience as a disabled person; my experience as the chairman of a DPULO; my experience as a trustee of a DPULO; and my full membership of a DPULO. Once this part of the process had been completed, the category names were reviewed, and modified if this was considered appropriate. Those responses that did not obviously fall into a specific category were assigned to one named Miscellaneous for subsequent review. A further analysis was then undertaken that compared and contrasted the category names so that those considered to be similar were combined under the most appropriate name (Strauss and Corbin, 1990). The contents of the Miscellaneous category were also reviewed and, if appropriate, individual responses were moved to one of the other categories. A final review resulted in a total of fifteen single responses remaining in the miscellaneous

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category. Examples of these responses included single word answers such as 'access' and 'citizenship' without any further explanation or context, which meant they neither appeared to fit one of the existing categories or provide additional insights concerning the DPULOs involved in my research. Consequently, I considered these responses to be too limited in nature and not relevant or of influence to the overall outcome of the study.

The SurveyMonkey (SurveyMonkey Inc., 2018) tools presented the results of the survey in both tabular and graphical formats (see chapter 7).

In the next section, I will discuss the ethical considerations of my research.

5.3 Ethical considerations

Before I embarked on the two stages of research described above, I followed the defined procedures for ethical approval for research with human participants as specified in the ARU Ethics Policy and Code of Practice for the Conduct of Research (ARU, 2014). I obtained the required ethical approval for my research from the Faculty Research Ethics Panel (FREP). The panel confirmed that I had applied the relevant criteria from the 22 provisions stated in the ARU Research Ethics Application Form (ARU, 2014) that fulfilled the requirements for my ethics application.

For instance, I identified elements from the provisions so that: informed consent was freely given by my participants; research was fully and meaningfully explained to my participants and information was provided about how data was to be disseminated; my participants were told about their right to refuse to take part in the research; my participants were told that all personal data would remain confidential; and my participants were made aware of their right to withdraw from the research at any time (Backhouse, Day and Corti, 2008). A letter confirming the approval of my ethics application (project number 11/045) is shown in appendix 5.

Ali and Kelly (2004) suggested that harm and its effects are part of the ethical decision-making process. The term 'beneficence' is the principle that all research should have the potential to benefit someone while non-maleficence is the principle

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dictating that harm should not come to individuals as a result of their participation in a research project. Harm can be physical, emotional, social and financial (Ali and Kelly, 2004).

Gelling (2015), in his online ethics blog, outlined five different categories to help researchers identify, predict and prepare for the possible side-effects of research. Of these, my research would fall into the no anticipated effects category, since the topic area was not obviously sensitive or likely to cause distress. However, because of the small-scale nature of stage 1 of my research, it was arguable that a breach of confidentiality could have caused social and financial harm to the DPULOs. Therefore, I ensured that the anonymity of the CEOs who agreed to take part in my research and their organisations was protected. This was achieved in three key ways.

Firstly, all identifying information on the recorded interviews was omitted from the written transcripts. Secondly, the CEOs were identified by unique numbers, and randomly selected pseudonyms were allocated to the DPULOs. Lastly, the recorded interviews and written transcripts that had previously been kept in a secure location would be destroyed when the study was completed.

Earlier in this chapter, I provided an explanation for my adoption of the transformative paradigm and described the characteristics of its individual components in terms of my own research.

I noted that the axiology of the transformative paradigm was concerned with moral behaviour in dealing with my research participants (Mertens, 2007, 2012) and it was this aspect of the ethical principles that I felt required further attention.

Two factors that I considered to be significant in terms of ethical principles within my research were those concerned with power relations between myself as a researcher and my research participants (Barton, 2005), and issues of accountability to the stakeholders interested in my research outcomes (Barnes, 2003).

I decided that these issues would be of particular importance when I explored with my participants such areas as finance, future strategic plans and business relationships, and their views that the disclosure of sensitive data might be of value

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to my organisation as a potential competitor. I therefore tried to ensure that my research was undertaken cognisant with these issues and that the participants saw me as an informed but independent researcher and not as a threat to their organisations (Barton, 2005). However, given my background as the chairman and a trustee of a DPULO I was conscious of potential adverse power relationships between myself as a researcher and the people researched.

It was my intention that adherence to the principles of the transformative paradigm would give the participants control over their involvement with the research processes and the stakeholder's choice over whether they adopted the final outcomes (Mertens, 2012). I decided that, where appropriate, it was important to put my skills and knowledge at the disposal of my participants and their organisations in order to fully involve them in the research (Barnes and Roulstone, 2005). This included: giving the participants control over the time and place of the interview; ensuring that the location of the interview was accessible and refreshments were available; and enabling the participants to have a break or to stop the interview at any time.

These factors supported me in ensuring that this study would provide both a contribution to knowledge and a contribution to practice in the area of disabled people and their organisations (Oliver, 1997).

5.4 Trustworthiness in qualitative research

The concepts of reliability and validity in research originated in the development of the positivist or scientific paradigm (Golafshani, 2003) where the characteristics of the methods used and the data collected were based on empirical certainty (Morse et al., 2002). However, as my research was conducted using the transformative paradigm, I agreed with Shenton's (2004, p.63) suggestion that 'new criteria for determining reliability and validity' should be adopted in order to justify the credibility of my research.

This suggestion also concurred with Mertens' (2007) position on research credibility. Shenton (2004, p.63) cited Guba (1981) 'who proposes four criteria that he believes should be considered by qualitative researchers in pursuit of a trustworthy study.' I therefore concluded that the four criteria 'a) credibility (in preference to internal validity); b) transferability (in preference to internal validity/generalizability); c)

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dependability (in preference to reliability); d) conformability (in preference to objectivity)' (Shenton, 2004, p.64) were appropriate measures for the trustworthiness of the qualitative section of my research.

5.4.1 Credibility

Shenton (2004) described 14 provisions that he suggested might be used by qualitative researchers in order to promote the trustworthiness of their research. As far as possible, I have applied these provisions to my own research. For instance: I adopted a well-established research methodology; I was previously familiar with the culture and values of DPULO's; I used a two-stage sequential process to ensure triangulation in the data collection; I encouraged my participants to be frank and honest in their responses; and I took part in regular research evaluations with my research team and my peers. Therefore, I considered that my research was credible.

5.4.2 Transferability

In discussing the work of Bassey (1981), Shenton (2004, p.69) noted that 'if practitioners believe their situations to be similar to that described in the study, they may relate the findings to their own positions'. Denscombe (1998) defined this process as transferability of the research outcomes.

I have attempted to provide sufficient contextual information about the study, including in particular my research design, data collection methods and data analysis, so that a reader might consider a transfer of the outcomes to their own situation (Guba and Lincoln, 1985; Firestone, 1993). However, I have fully accepted that it was the responsibility of the reader to ensure that the outcomes were indeed applicable to their situation.

5.4.3 Dependability

Guba and Lincoln (1985) stated that an essential criterion for claiming quality in qualitative research was through the concept of dependability. Shenton (2004, p.70) suggested that in order to ensure dependability in qualitative research, the design processes 'should be reported in detail, thereby enabling a future researcher to repeat the work, if not necessarily to gain the same results' and to

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demonstrate that correct research practices have been followed. Shenton (2004) argued that three provisions should be detailed in a study that included qualitative data in order to demonstrate the dependability of the research.

I fulfilled the requirements of these three provisions in my research as follows: I have fully described the research design, its implementation and its planning and execution; I have explained the field-work and the operational detail of the data gathering; and I have provided a reflective appraisal of the study, evaluating the effectiveness of the process of inquiry.

The first two of these provisions have been fully described in the methodology and research design chapters of this study (see chapters 4 and 5). However, the third provision was appraised during a critical review of this research study presented in the latter chapters of this thesis (see chapter 9).

Therefore, I believed that I could claim that my research was dependable

5.4.4 Confirmability

As a full member and long-term trustee of a DPULO, I was conscious that I had knowledge and experience that might bias my research. However, as far as possible, I endeavoured to ensure that the research outcomes reflected the lived experiences and views of my participants (Shenton, 2014) rather than those of myself. My intention with the use of methods inherent in the transformative research paradigm was to promote the role of triangulation in the data collection process and minimise the effects of researcher bias. I have described in detail the methodology and research design so that a reader might follow the procedures and decisions taken in a logical manner.

Therefore, I believed that my research met the requirements of confirmability.

5.5 Reliability and validity in quantitative research

Golafshani (2003) stated that the quantitative outcomes of a survey could be tested to ensure repeatability and replicability by using the concepts of reliability and validity. Hussey and Hussey (1997, p.57) stated that 'if a research finding can

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be repeated, it is reliable. In other words, if you or anyone else were to repeat the research, you or they should be able to obtain the same results'. To try and ensure my survey data was reliable, I removed (as far as was possible) ambiguities in the language and in the questions. The survey was piloted with my two supervisors, my personal assistant and the ODI senior executive. Where issues in understanding the question could have affected the answers they gave, I revised the questions and checked again with my supervisors, my personal assistant and the ODI senior executive to ensure that they were interpreting the question in the same way (Golafshani, 2003).

Hussey and Hussey (1997, p.57) stated that 'validity is the extent to which the research findings accurately represent what is really happening in the situation'. As well as the pilot study, I ensured that the questions were appropriate as they were informed by my first-stage research.

The open questions were arguably more problematic because they were more open to interpretation. This was because they were less specific in order to encourage a breadth of concepts (see limitations in the concluding chapters). This meant I had to be more circumspect in my analysis of the data (Creswell and Plano Clark, 2007; Creswell, 2012).

5.6 Summary

This chapter described the key principles behind the research design for this study and explained the methodological approach I selected in undertaking the research.

As a long-term member and trustee of a DPULO, I was conscious that I was both the researcher and part of the community being researched. Therefore, in undertaking the research, my intention was to identify the challenges being faced by DPULOs without my personal experiences influencing the outcomes. I wanted to work with these organisations in order to identify the factors that might support their future stability. Consequently, I concluded that a methodology informed by the transformative research paradigm was appropriate for this study.

I followed the recommendations of Mertens (2012) who suggested the use of mixed methods within the transformative paradigm in order to collect a combination of

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qualitative and quantitative data. I decided to use a two-stage sequential design where stage 1 informed the design of stage 2 and where the stages consisted of semi-structured interviews and a survey respectively. The findings from the stage 2 survey were compared and contrasted with the findings from the stage 1 interviews in order to triangulate the research outcomes.

As my research was conducted using the transformative paradigm, I concluded that the traditional positivistic measures of reliability and validity were inappropriate for the qualitative stage of my research. Therefore, I elected to evaluate stage 1 against the concepts of credibility, transferability, dependability and confirmability. However, I decided that the concepts of reliability and validity were suitable measures for the stage 2 survey.

In the next chapter, I will present the process of analysis and the findings from the semi-structured interviews.

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CHAPTER 6: FINDINGS 2 – SEMI-STRUCTURED INTERVIEWS

6.1 Introduction

In the previous chapter, I described the data collection methods and the process of analysis for the two stages of research. In addition, I discussed the ethical issues inherent in this study. The concepts of credibility, transferability, dependability, confirmability, reliability and validity, were considered as being suitable values for the evaluation of this research.

This chapter will present the findings from the stage 1 semi-structured interviews, where the interviews were undertaken with the CEOs of 12 disabled people's user-led organisations (DPULO)s. The findings are divided into sections that directly relate to the three research questions for this study as follows:

1. The historical roots of DPULOs
2. The structures and characteristics of DPULOs
3. The key challenges for DPULOs
4. Future opportunities for DPULOs

6.2 Presenting the research findings

Burnard (2004) suggested that there were two main methods of presenting qualitative research findings. One method involved reporting the 'key findings under each main theme or category, using verbatim quotes to illustrate those findings' (Burnard et al., 2008, p.431). This was then supported 'by a linking, separate discussion chapter in which the findings are discussed in relation to existing research' (Burnard et al., 2008, p.431). Burnard et al. (2008) referred to this method as the traditional approach to presenting research findings.

In contrast, the alternative method repeated the initial process but incorporated 'the discussion into the findings chapter' (Burnard et al., 2008, p.431). As the outcome from the analysis of the semi-structured interview transcripts was intended to both inform and complement the survey questions, I considered that the traditional approach was the most appropriate way to present my findings.

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The reasons for the use of the traditional method included: the research design was based on a two-stage sequential approach; and the findings from both stages would be used together in a single discussion chapter.

As previously stated, the interview questions for the stage 1 semi-structured interviews were chosen because of my personal experience as a disabled person, involvement with my own DPULO, and the two literature review chapters, therefore both the academic literature and my lived experience informed the final research questions. To ensure anonymity, the names and genders of the participants have not been identified, only the type of the organisation (M = Mature; E = Established; and F = Fledgling). For the date of establishment and physical location please see table 4 below. For the convenience of the reader, table 4 is a repeat of the table found in the methods chapter (see chapter 5).

DPULO PSEUDONYM	DATE ESTABLISHED	PHYSICAL LOCATION
M1	1981	LONDON
M2	1975 (1980s)	LONDON
M3	1985	NORTH WEST
E1	1997	SOUTH WEST
E2	1995	WEST MIDLANDS
E3	1995	SOUTH EAST
E4	1997	NORTH EAST
E5	1992	NORTH WEST
F1	2005	SOUTH EAST
F2	2000	SOUTH WEST
F3	2007	SOUTH WEST
F4	2009	NORTH WEST

Table 4: *Pseudonyms, date established and physical locations for the 12 DPULOs who took part in the stage 1 research (copy of table 3 for readers' convenience).*

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6.3 The findings

6.3.1 The historical roots of DPULOs

In this section, I explore the origins of the organisations in terms of the dates they were established, by whom and why. The data revealed a number of interesting aspects about the role of non-disabled people in the first wave of DPULOs that emerged in the 1970s and early 1980s, where both philanthropic, if not paternalistic, interventions by non-disabled people who were doing 'good works' in leading the development of DPULOs can be observed. However, by the mid-1980s the power balance shifted, and examples of organisations established and led by disabled people emerged. This latter development can be considered as a 'zenith' point which brought together four catalytic developments in the disability movement described further below. The core ethos and value base underlying the reasons for establishing the organisations was illustrated in the language used by the CEOs who repeatedly refer to the importance of choice and control in facilitating an inclusive society.

6.3.1.1 When were the organisations established?

The initial questioning of the CEOs was intended to confirm the year of establishment of their organisation. This was to ensure that the sample selected reflected the age ranges of organisations as specified in the research methods (see chapter 4).

The analysis confirmed that there were two organisations established between 1980 and 1989 inclusive (M1 and M3), five established between 1990 and 1999 (E1 to E5) and four established after 1999 (F1 to F4). However, one CEO stated that his/her organisation:

'... was set-up in 1975 by non-disabled people but in the 1980s it was taken over by disabled people and it became a user-led organisation' (CEO, M2).

Therefore, I considered for the purposes of this research that M2 was established in the 1980s.

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6.3.1.2 Who established the organisations?

The CEOs were then questioned about who had established their organisations. The majority of the CEOs in the "M" category (M1 and M2) stated that their organisations had initially been established by non-disabled people but indicated that over time they were subsequently taken over and run by disabled people:

'...it was started in 1981 by some nice ... ladies who weren't disabled and wanted to do good works. I never met them so I'm just assuming this is how it worked, and it ran as a very small organisation for a few years and was, with the changes, you know in the, with the changes in philosophy things we've been discussing and the move towards user involvement and ultimately user-leadership, moved over from being an organisation for disabled people run by non-disabled people to being an organisation run by and for disabled people, which is what it is now' (CEO, M1).

'...was set-up in 1975 by non-disabled people but in the 1980s it was taken-over by disabled people and it became a user-led organisation. So, we've been going ever since' (CEO, M2).

In contrast to M1 and M2, the CEO of M3 stated that:

'We were formally constituted in 1985 after a meeting in July that year which was made-up of over 100 disabled people' (CEO, M3).

The changes described by the CEOs from M1 and M2 indicated that during the 1980s there was a significant shift in that disability activists felt that organisations for disabled people should be run and controlled by disabled people. The establishment of M3 in the mid-1980s by disabled people supported this position.

Literature review 1 (chapter 2) demonstrates that there was a defining moment during the early 1980s when disabled people wanted to take control over their own lives.

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Influences that encouraged this movement included: the Union of the Physically Impaired against Segregation (UPIAS) (1976), the International Year of Disabled Persons (IYDP) (Taylor, 1981; 1993), the Independent Living Movement in the USA (ILM) (Evans, 2003; Pridmore, 2006) and the social model of disability (Oliver, 1983, 1990a). The statements made by the CEOs of M1, M2 and M3 strongly supported this position.

Half of the CEOs from the "E" and "F" categories indicated that their organisations had been established by disabled people. For example:

'The charity was initially founded as the... in 1997 by a small group of disabled people who felt they needed a representative voice in... an opportunity through which they could engage with professionals and an information and advice service for disabled people' (CEO, E4).

'...it was established in 2007 under its current name, the... but we built upon the original constitution of... which had been established in 1999. So, the company and its a limited company has been in existence since then but it was changed really to reflect the fact that we didn't want to just be representing the interests of people using social care services but disabled people in... So, in order to create the new organisation we set-up an alliance of other user-led disabled people's organisations in... in order to create a coalition that involved individual disabled people but also disabled people's organisations that met the minimum criteria around governance. So, we were set-up by disabled people' (CEO, F3).

The comments by the six CEOs in the "E" and "F" categories demonstrated that by the 1990s, disabled people had become sufficiently empowered to make decisions about who ran and controlled their organisations. Literature review 1 (chapter 2) demonstrated that developments such as the influence of, and support from, the British Council of Organisations of Disabled People (BCODP) (Barnes, 2007) and the growth of organisations in the 1980s that were run and controlled by disabled people (Evans, 2003) also provided the inspiration for the subsequent establishment of other DPULOs.

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However, there were nuances in the data revealing the ways in which officers from statutory services worked alongside disabled people to develop their organisations. For example, in contrast to the comments made by the previous six CEOs, the CEOs of E2 and F3 indicated that both disabled people and officers from government agencies had been involved in the establishment of their organisations:

'Well, the initial idea came from... health authority. There was some capital funding available from... regional health authority and they asked around if anyone had any ideas for developments that sort of thing and a single chap at... health authority had the idea. At the time, he called it a disabled health centre and got together a group of people and they developed the idea to set-up some sort of disability resource centre. There had been some research done in the mid-1990s and one of the things that had come-out was there was no co-ordination of disabled people's services in the area and that had come from disabled people and professionals working in the area. So, that really sewed the seed for having some sort of service and they had a vague idea that they wanted an organisation to co-ordinate disability services but to also bring-in new services and to bring people together' (CEO, E2).

'Then what happened in 2009... the local authority placed a contract with another organisation in the region to establish our organisation. So, they commissioned this other organisation to bring together an initial governing body, like a shadow board, to take the organisation through to company registration and becoming a charitable organisation... they then developed this vision which was for a local Centre for Independent Living locally and they were thinking we could have a user-led organisation that can become the hub for that and also drive forward changes...' (CEO, F4).

The CEOs of E2 and F4 demonstrated that local and regional government agencies provided financial support to establish and develop their organisations. The intention of these government agencies was to help create a focus for locally provided independent living services for disabled people. The impetus for these developments was subsequently reinforced in the new Labour government's Improving the Life Chances of Disabled People policy document (PMSU, 2005).

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The role therefore of the non-disabled person could arguably be seen as shifting from philanthropic to enabling someone who provides resources (such as funding) to enable disabled people to lead their own organisation (rather than leading it for them). For example, the CEO from E1 stated that his/her organisation had been established by both disabled and non-disabled people:

'So, the organisation was a virtual organisation of disabled people and non-disabled people meeting in each-other's front rooms... and the reason they got together initially was because they were very concerned about having direct payments in the county... They were also very concerned to have control over how direct payments evolved in the county. So there was an organisation run by non-disabled people who said we'll take on the support for direct payments and ... other people said; no, we think this is something that disabled people should do for themselves' (CEO, E1).

In contrast to the previous examples, E1 was established by both disabled and non-disabled people in order to influence how direct payments were introduced and developed within their county as a local authority area. However, while working together to enable direct payments to be managed, the quote above also illustrated the tension inherent in the relationship and E1 subsequently developed into a DPULO.

6.3.1.3 Why were the organisations established?

Of the CEOs interviewed, five were personally involved in the creation of their organisation. Consequently, they were able to discuss from a first-hand perspective the reasons why their organisation was established. Half of the CEOs were not involved in the creation of their organisation, so, were only able to provide a perspective that was not based on their personal experience. One CEO (M3) did not provide any obvious explanation of the reasons why his/her organisation was established. Examples of the CEOs' explanations of why their organisations were established included campaigning. This was primarily from the longer-standing organisations (M) and reflected their development during the rise of the disability movement in the 1980s:

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'We have very strong roots in campaigning for disabled people's rights and the values of the organisation were to promote the human rights of disabled people and to tackle any barriers that exist. So, the key message was to promote human rights and I think we've stayed true to that' (CEO, M2).

All of the CEOs, but particularly those from organisations formed from the 1990s onwards, stressed the values of inclusive and independent living. The concept of choice and control was the fundamental pillar that achieved these values:

'Disability... has a 15-year history of facilitating the full inclusion of disabled people in... with a mission to facilitate a fully inclusive society in... through empowering disabled people to achieve independence, choice and control' (CEO, E4).

The value of peer support – being with people who share the same or a similar situation based on their impairments and experiences of being disabled by society was also mentioned by some CEOs:

'We weren't incorporated in 1992 but it started off in 1992... as a sort of support network for disabled people, so very much a low key I suppose more peer supportive group if you like... We started delivering the direct payments support service contract in 1998...' (CEO, E5).

'It was set up in 2005 and it was in response to the report that came out from the government at that time Improving the Life Chances of Disabled People... so, there needed to be an organisation... a centre for independent living. So, it's around supporting people to have choice and control in their everyday lives and helping them to understand what is available to them. So, that's what... it's...enabling people to have choice and control really' (CEO, F1).

The majority of the CEOs (10 out of 12) indicated that their organisations had been established with aims that included: developing peer support; enhancing disability rights; and the principles of choice and control for disabled people.

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These aims both reflected the recommendations in the UPIAS (1976) Fundamental Principles of Disability document and importantly highlight the core value base of the disability movement in the UK.

These values and the types of activities and services that flow from them (see section 6.3) can be seen in contrast to the types of organisations initially established by non-disabled people in the 1970s and early 1980s. As the CEO of M1 stated:

'Initially it was very much an organisation that provided little bits of help for disabled people and even when I first joined the organisation 12 years ago it had a group holiday project and it had a group leisure activity project and that was the focus' (CEO, M1).

This organisation was established by non-disabled people, through the concept of 'good works' to assist disabled people in undertaking social activities. The provision of such 'good works' were defined by French and Swain (2004) as the personal tragedy theory of disability, where disabled people were viewed by society as being weak, vulnerable and in need of help (Hunt, 1966).

However, the subsequent empowerment of disabled people during the early 1980s resulted in a fundamental shift in the provision of these 'good works'. These changes were illustrated by the CEO of M2 who pointed out that:

'... but I'm really proud of our social inclusion network... in rotation they have a writing group one week and an art group the next week and a discussion group... we also have picnics in the park and that sort of thing but it's strongly user-led and people sort out their own refreshments and they get their own food ready and things like that... when you talk about social activities it's like disabled people being bussed to the park but it's not like that. Everyone, the staff and the disabled people together, it's not a patronising thing at all' (CEO, M2).

The themes that were woven through the accounts of how and why these organisations developed are echoed and further elaborated in the next section. The section outlines how the organisations were structured and the way in which they operated.

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6.3.2 The structures and characteristics of DPULOs

This section of the findings outlined the composition of DPULOs in terms of their legal status, boards, employees and membership. The core values of the participating DPULOs are explored in terms of their ethos and service delivery. Although all of the organisations were facing similar challenges, the language used by the organisations revealed some nuances in terms of the particular struggle that the mature (M) organisations, that were founded primarily as campaigning organisations, faced in adapting to the relatively new contract culture. In the broadest sense, the data raises more profound questions (explored in the discussion in chapter 8) about identity politics and what it means to be a 'DPULO' in contemporary times.

6.3.2.1 Trustee/director boards

In response to questions regarding the composition of their boards, an overwhelming majority (11 of 12) CEOs indicated that at least 75% of trustees/directors were disabled people. For some, this figure is a strongly held value and being an organisation run for and by people with direct experience of disability is paramount, for example:

'They are all disabled people on the board. We were thinking about co-opting a non-disabled person because we've got a couple of vacancies at the moment but we would rather not. So, we're fairly pure' (CEO, M2).

Other responses indicate an interpretation that broadens this definition to include close relatives of the disabled person who will also bring experiential knowledge as a carer:

'We have got a board of eight I think... yes, eight people and of the eight, seven are disabled people and one, he's not disabled himself but he is the father of a disabled daughter. Our constitution says 75% of our board members have to be disabled people' (CEO, E2).

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'... our board is made-up of... we have 10 people who are disabled people and are service users themselves... and two who are carers and two are professional people in terms of one is the solicitor, local solicitor and one is the chief executive of the mental health project in... we have over 75% of our (board) members are disabled people (CEO, F1).

The comments by the 11 CEOs demonstrated that their organisations fulfilled the Office for Disability Issues (ODI) criterion that required a minimum membership of 75% of disabled people on their boards in order to be considered as DPULOs (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). A further criterion specified by the ODI defined a DPULO as an organisation that was led and controlled by disabled people (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). However, the quotes indicated the different ways in which this requirement might be interpreted.

Other CEOs still considered themselves to be running a DPULO but had moved away from the 75% criterion. For example, the CEO of E1 stated that only 51% of his/her organisation's board consisted of family carers and disabled people:

'... constitutionally, we were 75%... 75% disabled people controlling the organisation and today, it's 51% family carers and disabled people. We made that change... to include family carers... could only be associate members and therefore didn't have voting rights but now they do have voting rights and that was important to us because increasingly we felt that we were supporting family carers who supported disabled people and that needed to be recognised somewhere within our constitution' (CEO, E1).

However, half of the CEOs, including the CEO of E1, quoted the exact figure of 75% when they were questioned about the percentage of disabled people on their trustee/director board. This suggested that these CEOs were familiar with at least one of the ODI criteria that defined organisations as DPULOs and this had influenced the constituency of their boards (ODI, 2011, cited in Bott, Sweeny and Watts, 2013).

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6.3.2.2 Employees/volunteers

The interview transcripts showed that all 12 of the CEOs were dedicated to the ODI criterion of being committed to employing disabled people in their organisations (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). However, the percentage of people with lived experience of disability varied from one third to 100%:

'In terms of our staff members, we will only employ disabled people at our organisation... so our staff profile is 100% disabled people' (CEO, M3).

'Prior to the reorganisation earlier this year, 52% of our staff members had a personal experience of disability... we are going to re-run the staff survey in the Autumn' (CEO, E3).

'We strive very hard with recruitment... employment opportunities for people with impairments so that they can work for us in jobs that actually do make a difference... about a third of our staff have an impairment. The staff that I inherited through... over half of them had an impairment from the original team' (CEO, F4).

While the CEOs were not specifically asked about their policy on the recruitment of disabled volunteers, three provided information that was considered to be relevant to this research. This was because volunteering offered other opportunities for disabled people to gain work experience and develop skills:

'We've then got our volunteer service, so we've got a volunteer co-ordinator and he supports volunteers within the organisation to both develop their skills and support the organisation with various things. So, Monday afternoon... I'm thinking what we've got going on... We are a UK online service, so we've got a number of volunteers this afternoon that are in supporting people to use IT and then we have volunteers that do the disability equality training. We've got a woman in at the moment, she's working on reception and she does Monday's and Tuesday's reception... we involve disabled people, we have a mix of people.'

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So the deaf awareness for example is done by a deaf woman, she's deaf but disabled people are certainly involved in the design of the courses and delivering the training' (CEO, E2).

'... if you take our advocates who are volunteers they are 100% disabled people... it's only that percentage comes down when the majority work with family support. So, I reckon we have got only 30% overall of our volunteers are disabled people but that is because of the family support service... if you took those figures out of the equation and just looked at things like advocacy and the administration staff that we have here that support us on a voluntary basis, it would be 100%' (CEO, E5).

'All our volunteers are disabled people... we provide volunteering opportunities for people that have impairments...' (CEO, F4)

The comments above indicated that these CEOs were committed to the recruitment of disabled volunteers into their organisations. This policy further contributed to the fulfilment of the ODI criterion for these organisations to be considered to be DPULOs (ODI, 2011, cited in Bott, Sweeny and Watts, 2013).

6.3.2.3 Membership

The majority of the CEOs (7 of 12) indicated that the constitution of their organisation could include up to three different categories of membership. The categories' were: full membership; affiliate membership; and associate membership. These membership categories included individual disabled people or organisations sympathetic and supportive of the work of the DPULOs. For example:

'... we have 3 types of membership. Full members, which are disabled people who live, work or have their education in.... Affiliate members, which are organisations that support the values of... and associate membership, which are disabled people or organisations that live outside of... but support our values' (CEO, E3).

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'We are a membership and representational body... Full membership is open to individuals only and must comprise a minimum 51% disabled people... Associate membership is open to organisations from any sector with an interest in supporting our work... they vary from adult social care to voluntary and private organisations' (CEO, E4).

'... in terms of membership... our membership is made-up of people who use end services. So, it's all the disabled people that are kind of full members of the organisation... and then we have associate members in terms of local professionals or people from the local authority' (CEO, F1).

The CEOs stated that their associate and affiliate categories included members such as: local authorities; private sector and voluntary organisations; carers and other professionals; and other interested parties.

However, the CEO of F2 indicated that his/her organisation's constitution only consisted of one membership category and that was for disabled people:

'We've got... members... all are disabled people. There might be a few carers in that but we're tied in with full membership for disabled people... In terms of associate members, we don't have a category for that' (CEO, F2).

There were eight CEOs who stated that only disabled people could be full members of their organisation. By offering a membership category that included only disabled people as full members, the organisations could be described as fully user-led and defined as DPULOs under the ODI definition of being run and controlled by disabled people (ODI, 2011, cited in Bott, Sweeny and Watts, 2013).

In contrast, the CEO of M3 stated that non-disabled people could be classed as full members, but his/her organisation had a constitution that ensured only disabled people were able to serve on the executive council:

'... although anyone can become a member, only disabled people can be elected onto our executive council' (CEO, M3).

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The CEO of M3 stated that only disabled people could be members of the executive council. It could therefore be concluded that the disabled membership held a position of primacy within the organisation. As a consequence, under the ODI requirement of being run and controlled by disabled people, M3 could also be defined as fulfilling the relevant criterion to be considered as a DPULO (ODI, 2011, cited in Bott, Sweeny and Watts, 2013).

Of the remaining three CEOs, those of M1 and M2 did not provide any obvious description of the membership profile of their organisation. In addition, at the time of interview, F4 had only recently been established. Consequently, the CEO indicated that his/her board of trustees had not yet introduced a membership policy:

'We're reviewing our membership at the moment and it's an area that a small number of people on our board are really interested in offering a membership scheme to individuals but have yet to be clear about how that works and how much it costs and how you do it effectively' (CEO, F4).

However, earlier in the interview the CEO of F4 noted that the initial concept of the organisation encompassed:

'... both disabled and deaf residents being involved and as part of that they then developed this vision which was for a local centre of independent living locally and they were thinking we could have a user-led organisation that can become the hub for that and also drive forward changes' (CEO, F4).

As detailed in literature review 2 (chapter 3), the ODI extended their definition of a DPULO to include those organisations that were working towards the attainment of the four stated criteria (Turnbull, 2012). Therefore, under these revised conditions, organisations such as F4 could also be considered to be DPULOs. However, the quotes suggested that there were differences in the views between DPULOs as to the acceptability, role and place of people without direct experience of disability, whether that was of relatives (indirect experience of disability but direct experience as a carer) or other individuals/organisations that offered support to DPULOs but without any lived experience.

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6.3.2.4 Legal structure

In response to questions regarding their legal structure, the majority of CEOs (9 of 12) stated that their organisations were registered as both charities and companies limited by guarantee. The data showed that the legal status of some organisations was determined by staff capacity and the time taken to navigate the bureaucratic hurdles in registering as a charity. However, for one DPULO in particular, the notion and symbolism of being a 'charity' was in tension with the disability movement:

'We are a company limited by guarantee and also a charity... we have one subsidiary trading company and that was established about 15 months ago, which is the governance vehicle with a company limited by share of which there is one share of which... is the shareholder' (CEO, E3).

'We are a charity and a company limited by guarantee at the moment. We are looking at exploring alternative organisational structures and moving forward in October. We have got an external facilitator doing that to walk us through the rules so that the board are clear about either intending to stay as we are or looking at an alternative as the name would suggest in terms of exploring organisational structures. I don't know whether we will move-over to more of a social enterprise model but for a number of reasons I don't know whether that will happen yet. I think that depends on weighing-up the pros and cons and will be a board decision' (CEO, E5).

'So, at the end of the last calendar year, November, December time, we became a company limited by guarantee and then in February became a charity' (CEO, F4).

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In contrast, the CEO of F3 stated that his/her organisation was registered as a limited company but not a charity:

'We are a limited company but not a charity. We have not done that yet. We have occasionally looked at the advantages but we are waiting for the new combined one because it will be less bureaucratic. We have not got the capacity to do all the paperwork for a charity' (CEO, F3).

This comment demonstrated that the CEO of F3 felt that his/her organisation did not have the staff capacity to undertake the regulatory processes necessary to become a charity.

The CEO of M3 stated that when his/her organisation was first established, the executive council agreed that they would not be registered with the Charity Commission:

'... the reason why the coalition is not a charity, was when the organisation was set-up there were debates about how the coalition wanted to distance itself from the traditional disability organisations and made statements that said we are not the same, we are not a charity. We are not going to raise money, we are not going to sort of betray ourselves by raising funds, we are going to do things in a different way so we can both change and influence those systems that disable us. We don't want to simply replicate the disability charity template like... and... which are emotive, manipulative, professional and well-resourced, often due to the fact that they will do just about anything to build-up their coffers' (CEO, M3).

The CEO of M3 suggested that the founders, in selecting the organisation's legal structure, decided that they did not want to be associated with the traditional views espoused by some of the larger national charities. In consequence, it would appear that the founders of M3 rejected these traditional views and favoured a structure that encompassed those values promoted by the disability activists involved in the UPIAS (1976) and in the social model of disability (Oliver, 1983; 1990a).

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However, there were indications that some of the CEOs and their trustee/director boards had either recently adapted, or were reviewing, the legal structures of their organisations in order to ensure that their ongoing operations remained fit for purpose.

6.3.2.5 Ethos and values

Some core themes ran throughout the data in this section, whether this was stated explicitly or implicitly in the quotes. The core values encompassed independent living, equality of opportunity, choice and control with a broader aim for an accessible world which was inclusive for disabled people. While there was consensus on these values, ways of achieving the overall aim varied as can be seen in other sections of this chapter.

An overwhelming majority (11 of 12) of the CEOs explicitly stated that the concept of independent living was an important value for their organisation. For example:

‘... our vision is to eradicate inequality for local disabled people and our mission is to empower local disabled people to have independence, choice and control over their lives...’ (CEO, E5).

‘... we have support around independent living and what’s available in the community... around supporting people on independent living...’ (CEO, F1).

‘... Also, promoting equality of opportunity and independent living for disabled people, that’s primarily what we’re about... that’s what we say in our mission statement to promote the rights of disabled people’ (CEO, F3).

Of these 11, three of the CEOs expanded the concept of independent living to include the principles as originated by the Derbyshire Centre for Inclusive Living (DCIL) and the Hampshire Centre for Independent Living (HCIL) during the 1980s (Davis and Mullender, 1993; Evans, 2003).

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For example:

'... in line with... as a whole also aim to inform and influence policies and service provision to be more inclusive in line with the seven needs of independent living' (CEO, M3).

'We try and follow the seven needs of disability, the original seven needs that were developed from Derbyshire... we have what we call the independent living unit and that's staffed by a... independent living worker' (CEO, E2).

'... everything we do is based on... the 12 pillars of independent living. We never actually stick it down in a strapline and say it means this' (CEO, F4).

The CEOs above indicated that they were aware of the principles of independent living that had been developed by the DCIL and HCIL (Davis and Mullender, 1993; Evans, 2003). The CEOs of M3 and E2 explicitly stated that their organisations followed the seven needs of independent living (Davis and Mullender, 1993). While the CEO of F4 emphasised the importance, in his/her words, of the 12 pillars of independent living to his/her organisation equating to the 12 needs of independent living as formulated by the HCIL (Evans, 2003).

The CEO of M1 did not explicitly mention the term 'independent living'. However, he/she indicated that choice and control for disabled people was a key value for his/her organisation:

'I'd love it if... I think for all organisations of our type, the aim is to do us out of a job because I'd like a world that is completely accessible and inclusive for disabled people... and if there's an inclusive world you don't need... it's all about access, it's all about inclusion, it's all about getting us as disabled people out there and getting us to do, you know, giving us the rights to do the same things as everyone else' (CEO, M1).

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Therefore, while not actually mentioning the term 'independent living', the CEO of M1 provided an impassioned dialogue that championed disability rights through the adoption of self-determination and access for disabled people.

All 12 of the CEOs demonstrated that their organisations embraced the principles of independent living as originally formulated by the Independent Living Movement (ILM) in the USA (Evans, 2003; Pridmore, 2006) and the values of choice and control for disabled people as outlined by the UPIAS (1976).

In terms of the social model of disability (Oliver, 1983; 1990a), an overwhelming majority (11 of 12 of the CEOs) indicated that their organisations supported its principles:

'We're fully committed to the social model of disability and this is the thing we want because we're user-led. All our trustees are disabled people and we're signed-up to the social model because inclusion is what we want to promote... we think that disabled people should have the same rights and all these barriers are there... they could be got rid of if people would be willing to understand that' (CEO, M2).

'Our mission is to enhance the everyday lives of disabled people and we are driven by the principles of... the social model of disability' (CEO, E3).

'... we're underpinned completely by the social model of disability which means when we talk about disabled people, we mean how society disables with disabling attitudes and the barriers that exclude us whatever our impairments' (CEO, E5).

The CEO of E1 did not specifically mention the term 'social model of disability' (Oliver, 1983; 1990a). However, the following response demonstrated that his/her organisation valued the general principles of the model and provided a convincing argument for his/her organisation's support of one of the key principles of the model in that the barriers faced by disabled people should be removed (Barnes, 2007):

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'our vision is that disabled people... be equally valued members of society and that drives everything that we do... it's identifying with the disabled person what it is they need to help them to live their life and reduce the barriers they face' (CEO, E1).

In spite of his/her organisation's support of the social model of disability (Oliver, 1983; 1990a), the CEO of M2 was aware that funding decisions for services were still made on a 'deficit model' and was honest about suggesting that disabled people should emphasise medical model thinking (Oliver, 1990a) during needs assessments in order to guarantee social care funding:

'... the welfare rights advocate always says that although we live by the social model of disability, we have to take the medical position by telling the person not to say what they can do, it's always about what you can't do, which is really frustrating' (CEO, M2).

The comment by the CEO of M2 stressed that in the view of his/her welfare rights advocate the principles inherent in the medical model of disability (Oliver, 1990a) should be used by disabled people to explain the barriers they face in order to obtain social care support.

The comments by the 11 CEOs demonstrated that their organisations fulfilled the ODI criterion that required them to be committed to the social model of disability (Oliver, 1983; 1990a) in order to be considered as DPULOs (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). In addition, the CEO of E3 referred to a third principle that he/she believed was espoused by the disability movement and mentioned in recent government policy documents:

'... if you look at the macro government policy there is a massive drive towards localism and choice and control. Now, those three elements have been around in the disability world for ever and ever and it now looks like national policy is caught-up with disability and there's a phrase in one of the government policies about 'Nothing About Us Without Us' and again, that comes from the disability movement.

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So, I think the greatest opportunity is what we've got and other organisations haven't got is that we've got credibility and legitimacy because we're run by disabled people for disabled people and you can't go out and buy that and that enables us to think very savvy about how we can engage with a whole range of organisations to allow them to buy part of what we offer whilst maintaining our independence and identity' (CEO, E3).

This CEO indicated that his/her organisation supported the key principle of 'Nothing About Us Without Us' (Charlton, 2000) and the associated values of localism and choice and control for disabled people. As a consequence, he/she felt that such values offered his/her organisation a position of 'credibility' and 'legitimacy' compared to other organisations. In addition, he/she believed that these values helped his/her organisation to gain a business advantage when working with other organisations.

While it was commonplace for most charities to undertake fundraising activities, the CEOs of E4 and E5 indicated that their organisations were ethically opposed to receiving charitable donations as these compromised the empowerment of their disabled members. In contrast, they preferred to focus on raising funds through the provision of contracted services:

'We have made a conscious decision to move away from the disempowering association of disability with charity. We are focused on becoming more business-like, a social enterprise, enhancing our professional image in various arenas and actively selling services as opposed to asking for donations etc.' (CEO, E4).

'We don't shake tins... no, we don't do fundraising, you know, we don't... we have very limited donations. We are predominately all contracts from a variety of different sources and generally contracts with the individual' (CEO, E5).

In contrast, the CEO of M2 indicated that his/her organisation undertook charitable fundraising but struggled with the ethical implications of such a policy:

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'One of the things that we do is annually we have a strategy half-day where we invite all our members, you know, we ask them what they want. They said they wanted more resources, for example, more advice and advocacy and some of them wanted to be more involved. For example, in a fundraising sub-committee to raise money for us and things like that. However, the issue of fundraising is always a thorny one because what is empowering and what is being patronising? They have a lot of arguments about that...' (CEO, M2).

These comments demonstrated that the concept of charitable fundraising was ethically unacceptable to these CEOs. In addition, in spite of the acceptance of such practices from his/her membership, the CEO of M2 acknowledged the demeaning nature of charitable fundraising and the moral dilemma being faced by some of his/her constituents. Literature review 1 (chapter 2) indicated that such practices had their roots in how disabled people were viewed by society as being weak, vulnerable and in need of help (Hunt, 1966). This patronising view of disabled people was described as the personal tragedy theory of disability (French and Swain, 2004). A key sub-theme in the data above was equality being identified as an inherent value for the DPULOs in these interviews (see the comments by the CEOs of M1, E5 and F3).

6.3.2.6 Services

As outlined in literature review 2 (chapter 3), the expectation of the then new Labour government's Improving the Life Chances of Disabled People policy document was that information and advice services for disabled people should be delivered by user-led organisations (ULOs) (PMSU, 2005).

A significant majority of the CEOs (10 of 12) indicated that their organisations provided information and advice services to a range of different clients such as: disabled people, including young disabled people; the general-public; local communities; health and social care departments; and other relevant professionals.

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The personalisation agenda was a major area of discussion for the CEOs, for example:

'The other big area we work in is the area of personal budgets and again, it's very much tied in with what I was just talking about... it's about supporting disabled people to support each other around knowledge around resources about the use of personal budgets... we provide an information and advice office...' (CEO, F1).

For one CEO, the focus on young people who were transitioning to adulthood was particularly important and entailed the development of new platforms of delivery:

'we've won quite a large award from... to develop... services around personalisation for young people. So, we're going to be developing some YouTube training materials and doing some videos and some films for young people who are in the transition period... because parents would have been receiving the personal budget or direct payment on their behalf and they're going to come to the stage where they will want to be doing it for themselves. So, we're going to be developing YouTube and all those trendy things so that young people can access it' (CEO, E2).

Other DPULOs were also moving into new online delivery platforms:

'... magazine... only disability awareness publication... distribution county-wide to public, health, social care... it is an essential tool for disseminating social care and health information, advice and support to disabled people and relevant professionals... enables us to take information out into local communities across... raise awareness, challenge inequalities... as and when the opportunity presents, we deliver conferences and events... we have a comprehensive web site available in 9 languages, 4 formats and Rok Talk enabled. It contains a range of useful information. We are also proactive on Facebook and Twitter... we are also further modernising online services through pursuing development of an app' (CEO, E4).

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'We also deliver an information service which includes things like a web site, drop-ins, outreach in community venues... and feedback forums. So, at the moment we're doing some work around what the changes will be... for disabled people... from DLA to PIP... we have information services that do mobile apps...and we have things like an online radio service...' (CEO, F4).

The CEOs provided details about the types of information and advice their organisations offered, these included: advising about social care support; challenging inequalities; raising awareness; and advising about changes in disability benefits. In addition, there were indications that digital technologies were being introduced and expanded in order to modernise the delivery of information and advice services and to ensure that these were accessible to all clients.

These organisations therefore complied with the requirements of the Improving the Life Chances of Disabled People policy document (PMSU, 2005). However, during the interviews, the CEOs of E1 and E3 did not provide any description of information and advice services provided by their organisations.

Half of the CEOs indicated that their organisations offered a range of advocacy services to their clients. For example:

'We have universal advice and advocacy and the funding for that is from the council and we've provided that in one form or another over the years... then we have general advocacy around issues around housing and employment and there's casework, that's normally not one-off but it's a series between the advocate and the client and it may involve representing the client at case panels or at social services or school, it's very wide and then we have a specialist welfare rights advocate, so that's about welfare rights that help people to claim and also involves going to tribunals on their behalf to challenge levels, you know, when they get a low award?' (CEO, M2).

'... we've got a number of advocacy services, one being general issue-based advocacy and one being mental capacity advocacy, which we do on a consulting basis with a range of other voluntary community and charity sector organisations.'

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We've also got continuing health care advocacy, predominantly for people who've had a negative decision with regards to continuing healthcare...' (CEO, E5).

'The services that we offer now are advocacy services both to individuals generally, anybody with an impairment across... and also specifically for individuals who have a learning difficulty. So, people with advocacy needs...' (CEO, F4).

The six CEOs outlined the range of advocacy services offered by their organisations, these included: welfare rights advocacy; mental capacity advocacy; continuing healthcare advocacy; and universal advice and advocacy. While these services were available to all disabled people, some were particularly aimed at those with learning disabilities, people experiencing problems with continuing healthcare support and people with mental health issues.

Literature review 2 (chapter 3) demonstrated that both the Improving the Life Chances of Disabled People policy document (PMSU, 2005) and the outcomes of research undertaken by Maynard Campbell, Maynard and Winchcombe (2007) recommended that advocacy was one of the services that ULOs should offer in order to support independent living for disabled people. However, in spite of these recommendations, six CEOs did not provide any obvious description of the provision of advocacy services by their organisations.

An overwhelming majority of the CEOs (10 of 12) indicated that their organisations offered independent living services to disabled people. For example:

'The other big area we work in is the area of personal budgets... In terms of service provision, we work with people with physical, sensory and hidden impairments... we support people to claim personal budgets...' (CEO, M1).

'We've got a payroll service for disabled individuals who employ their own staff... direct payments, access to work, a managed bank account and we've got a personal health budget service...' (CEO, E5).

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'... service level agreements with the Department of Adult Social Care... contracts with the Department for Children, Schools and Families... partnership contracts and contracts with the NHS... and through Personal Budget support services... we deliver payroll and managed account services for around 120 clients' (CEO, E4).

'... we also now have a contract to provide the direct payment support for people, that support service for people that have, you know, been in receipt of direct payments from the council' (CEO, F1).

The provision of independent living services by the 10 organisations included support for disabled people in areas such as: personal budgets; direct payments; managed accounts; personal health budgets; and access to work. Comments from the CEOs showed that their organisations offered a number of independent living services within a wide portfolio of support services under contract from local authorities and other government agencies. Literature review 2 (chapter 3) highlighted the Improving the Life Chances of Disabled People policy document (PMSU, 2005) in which it was claimed that funding for independent living services would come from health, social services and similar providers. The transcripts demonstrated that in certain circumstances these practices had been successfully implemented.

However, both the CEOs of M3 and F3 stated that they did not offer independent living services to disabled people funded by local authorities or other government agencies:

'We don't manage any payroll services or personal budgets on behalf of local authorities...' (CEO, M3).

'... personal budgets are offered by the others in the consortium. I think we felt it was quite important to be separate because of the issue of Chinese-walls when it comes to being involved in procuring services and it's important for the professionalism of these organisations that there should not be any cause of concern by statutory agencies' (CEO, F3).

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The CEO of M3 did not provide any obvious reasons why his/her organisation did not offer independent living services to disabled people. However, an investigation into the portfolio of services offered by M3 indicated that the organisation's primary aims were to provide support services to disabled people in the form of information, advice and consultation. However, it was unclear where the funding for these services was obtained.

In contrast, the CEO of F3 clearly stated that his/her organisation was responsible for the ancillary work that underpinned local authority contracts while other consortium members provided independent living services.

Just under half of the CEOs (5 of 12) indicated that their organisations offered commercial services. For example:

'... at the moment, we are setting-up a transcription service. When we produce our own publications, we do them in a variety of formats whether it's large print, we do those in various sizes, we do them on different coloured paper... we also do Braille, audio tapes, Easy Read, electronic text etcetera... seeing the skills and potentials of producing alternative formats and trying to generate income through that... that's in the early stages...' (CEO, M3)

'We also have a small number of what you would probably term commercial services around a Criminal Records Bureau service, disability equality training and conferencing service through the hire of our training and meeting rooms' (CEO, E3).

'We have kind of a trading and fundraising part to the organisation. We have meeting rooms at our offices that we hire, we sell RADAR keys and things like that and that's an area where we are looking to develop further to sell equipment and things' (CEO, F2).

The transcripts indicated that the five CEOs claimed that their organisations offered services that could be considered commercial in nature as they were intended to generate revenue from sources other than local authorities and government agencies.

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It was apparent that these so called commercial services were in fact the use of existing assets and services that were being offered to fee-paying external clients. There was no obvious evidence in the transcripts that the services had proffered any significant financial surplus. In addition to the services they currently provided, the CEOs of M3 and F2 indicated that they were in the process of testing the viability of new commercial services or identifying products or services that could be sold on a commercial basis.

6.3.2.7 Quality standards/feedback

While the CEOs were not specifically asked about quality standards, seven indicated that their organisations utilised a Quality Management System (QMS). These were discussed in context of concerns by DPULOs to be considered as professional and meeting the ISO framework:

'I think as an organisation, you know, we've developed... we're currently... we've got quality assurance systems in place and we're working towards Pqasso level 2... as an organisation we have a very good sort of back office, office management, financial management and all of those systems and we have all the policies in place and all the sort of procedures in place which everybody adheres to and which we develop regularly and I think all of those contribute towards our on-going professionalism' (CEO, M1).

'... as well as being professional by providing good quality services to the end users... we've introduced various standards and quality measures... we use Pqasso... and ISO 9001... the standards we're aspiring to are level 3 Pqasso but the measure is the ISO framework... the one feeds the other' (CEO, E1).

'I think it comes from that, ISO 9001, which underpins so much of what we do... it's the deadlines and it's all those areas that we work to make sure that services are hopefully delivered professionally from day one but it's then how we react when something goes wrong' (CEO, F2).

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The seven CEOs indicated that their organisations were registered for a range of QMSs including: Pqasso levels 1 and 2; ISO; Investors in People; Quality Mark; and Advice Service Agency quality mark (see for instance: Investors in People, 2017; NCVO, 2018; BSI, 2018). The CEOs suggested that these standards had supported the provision of good quality services and emphasised the professional nature of their organisations.

In contrast to these organisations, the CEO of F4 claimed that it was his/her intention to introduce QMSs in the future:

'... we're very business focused in terms of recording information and keeping things secure and data sensitive and all those kind of things. But we also look at things like ISO 9001 and Investors in People which is my next kind of big round of activity in terms of having standards that are understood by commissioners and industry and moving away from being grant focused and actually contract driven' (CEO, F4).

This comment demonstrated that although the CEO of F4 had not yet introduced QMSs, he/she understood the need for such standards in order to be recognised as being professional by funding agencies and other interested parties.

Of the remaining four CEOs, those of M2 and M3 did not provide any obvious indication that their organisations utilised QMSs. However, although the CEOs of E3 and F3 did not specifically state that their organisations adhered to such standards, they did comment on the importance of offering high quality services to their clients:

'I think it's quite simple and I think it is realising and recognising that disabled people want, demand, need, should have high quality services and if that is your principle, then you have to be professional in the way that you go about delivering that high quality' (CEO, E3).

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'... the quality monitoring... comes from having openness in communication and encouraging feedback from... the members of what the organisation is delivering for them and obviously from funders and other bodies with which we're involved to make sure people are providing the sort of involvement and contribution that they want... we've agreed outcomes and outputs for our core income because they want us to enable this and then we try to demonstrate in some numerical terms about how many people have been involved generally and communicated with...' (CEO, F3).

In addition, the CEOs of E2, E3 and F3 stated that their organisations utilised feedback mechanisms to evaluate the quality of the services they provided to clients:

'... but we also do service user questionnaires, we do two different types. We do one that is measuring the difference we make to an individual's life and then we do the other, which is about measuring our staff performance' (CEO, E2).

'I think we are into regular surveying of individuals about the quality of services that we provide, which is something we probably didn't do a few years ago and because of the nature of the organisation, co-producing all the services that we provide. By that I mean disabled people being involved in the development, the implementation, monitoring and evaluation of services and not just being seen as the recipient of services that we choose to deliver them' (CEO, E3).

'... we've managed to deliver because we've completed a whole commissioning cycle is that co-production, which starts with involvement and designing new services and then involvement in the evaluation and monitoring is that you can complete that circle and see that the service has been delivered is what people want and not what someone said that disabled people needed ...' (CEO, F3).

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The CEO of E5 specifically mentioned his/her organisation's complaints procedure as an additional feedback mechanism:

'... this is how you can contact me, if you're not happy with our services you can contact ..., this is our complaints procedure and when I came to see you, this is what we discussed' (CEO, E5).

In spite of not discussing specific QMSs, five of the CEOs demonstrated that they understood the need to provide their clients with high quality services through the utilisation of feedback mechanisms such as surveys.

In total, 10 of 12 CEOs indicated that through the introduction of QMSs or other feedback mechanisms, their organisations were able to maintain and improve the quality of the services they provided to their clients. Therefore, these organisations adhered to the principles, as outlined in literature review 2 (chapter 3), of the Improving the Life Chances of Disabled People policy document (PMSU, 2005) so that ULOs developed high quality services.

6.3.2.8 Training and development

In questions concerning training and development, just under half of the CEOs (five of 12) stated that an appraisal scheme was utilised in their organisation. For example:

'We've got all the staff appraisals, supervision, induction. I've gone backwards but yes, training and development we've always kept even when money has been tight...' (CEO, E2).

'So, annual appraisals, monthly supervision and that is all recorded. All staff have access to files. We've gone down a clear process where our HR advisors have worked with us to design these elements and it's all consistent and it all meets the guidance that's out there and we also do regular updates of those' (CEO, F4).

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The CEO of E2 also stated that his/her organisation appraised board members/trustees:

‘... we began to bring in a trustee appraisal system to see how we could support them in their development’ (CEO, F2).

A majority of the CEOs (9 of 12) indicated that their organisations offered training and development opportunities to their staff. For example:

‘We have a training budget for when staff identify training for the organisation as well as their personal development. We usually look quite favourably on that’ (CEO, M3).

‘As part of induction there is certain training that everybody has to do that’s compulsory. So, things like health and safety, fire, disability equality training, deaf awareness training, visual awareness training, we do all that and it’s compulsory and it’s then what people need for their particular jobs and beyond... I was allowed to go on a kind of secondment but continued to work here for two years to do some freelance consultancy work in another area because they saw that as a part of my continuing professional development’ (CEO, E2).

‘We also have training on a regular basis for staff. We’ve just looked at training now for this morning for the autumn and looking at what training needs to staff, the staff need in terms of the ones that we’ve just signed up for persons into thinking, persons into planning. Development, individual development plans for us as well’ (CEO, F1).

In addition to the staff, the CEO of E2 indicated that volunteers were also offered training and development opportunities:

‘Yes, we’ve always been strong on training and that’s for volunteers as well. The volunteers have a training budget, so they do training as well’ (CEO, E2).

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The CEO of E3 did not indicate if his/her organisation offered training and development opportunities to staff and volunteers. However, although the CEO of M1 did not specifically mention training and development, he/she acknowledged the need to identify an individual's latent skills for appropriate employment and this could be undertaken within his/her organisation:

'... what I'm starting to do is create routes into work within our organisation. As you might have picked up I'm not that keen on supporting people to become, you know, shelf-stackers at the local supermarket just so they can get off benefits, you know but I am interested in supporting people to use their skills effectively and our organisation is one place of doing that' (CEO, M1).

The majority of CEOs (10 of 12) indicated that training and development were essential in the creation of a skilled workforce. In addition, some of the CEOs expanded on this and suggested that senior staff were responsible for improving the skills of their workforce through the application of appraisals, training and development. These organisations therefore fulfilled the recommendations of the NCVO (2018) (see chapter 3) so that the voluntary sector should offer an appraisal scheme, training and development to all members of their workforce.

6.3.3 The key challenges for DPULOs

In this section, I outline the key challenges faced by the 12 DPULOs. Like all small third-sector organisations, DPULOs, in recent years, have been affected by the impact of austerity and neo-liberal policies that involved cuts to the statutory sector that have been the lifeblood of funding. However what is arguably unique to DPULOs is that they are founded on and developed from a knowledge base derived from direct experience. This is a feature that is both fundamental to the UK disability movement and one that has previously been valued by local authorities in terms of awarding contracts. However, as contracts start to be awarded primarily on cost and 'value for money' this precipitates the rise of large national organisations (usually with in-built bidding teams) who compete with local DPULOs for the same contracts. In addition, DPULOs begin to compete with each other for the same contracts. This causes tensions within the disability movement and exposes the weaknesses in their organisations.

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These organisations are used to working in a value-based system and who, by adhering to the strict criteria for a DPULO (at least 75% of the board being disabled people), find they don't always have the requisite skill base to win or deliver contracts in the new environment.

6.3.3.1 Financial constraints

In questions regarding key challenges, a majority of the CEOs (eight of 12), at the time of interview, indicated that financial constraints were affecting their organisations. For example:

'I would break the challenges down into the obvious financial ones. Money isn't as easy to come by now as it was even three years ago... five years ago... the public sector money is... there's not as much statutory sector money as there was and that means there's actually not, in reality, there's not as much money in general in terms of funding because there's a greater demand on the non-statutory sector funding on the trusts... everyone's fighting for a smaller pot of money' (CEO, M1).

'So external challenges... the cuts took from the government obviously were passed on to us and we had a 60% reduction in funding, that was in April 2010... we've been used to having this guaranteed income that we don't have anymore... Obviously we've got a reduction in funding, so, we've got a lack of guaranteed funding now for the agency and the agency is sort of the profit-making arm, you know and the profits go back into the organisation' (CEO, M2).

'... we lost all our revenue funding in February this year... is made up of 10 local authorities, so, we were funded through... and we were funded basically since we were formed by them and last year they announced that they were changing the formula. There was some kind of economic matrix that you have to fit in to and it was about the amount of money they were giving you and in return the amount of jobs that were created as a result. The weighting of quality and social impact was downgraded.

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You had a 25% to 50% weighting: now I think it's like 10 or 15%. So, I think we demonstrated how social equality and equality impact can have on the economy and the benefits it can bring to the region but in the end that didn't sway the funders and we lost all our revenue funding... this is a direct response of our government's economic policy and reduction of local authority funding... the local authorities have said they have been affected by central government policy' (CEO, M3).

The terminology is also interesting in the quotes below which illustrate the tension between retaining core values and finding a sustainable way forward that enables the organisation to deliver to those values:

'... there are two challenges and they are closely interrelated and one is trying to establish a viable business model that enables us to deliver our core aims around enhancing the everyday lives of disabled people and that's a challenge in terms... of recognising the financial constraints that are affecting all organisations... the second challenge is around finances which I think every chief executive would tell you exactly the same' (CEO, E3).

'... the challenges since 2010 have been... there was no funding to support the CIL... there was a basic core funding of £20,000 to pay for an office base... but it was manned by volunteers and the local authority at that point didn't see the necessity of funding the CIL... in 2010 I came to work here and we kind of got some funding from the Department of Health to build the capacity of the CIL and the local authority match funded that... was the first time we were able to employ people from January... that was the major challenge really... and from then until now it has been about us proving our worth...' (CEO, F1).

The CEOs indicated that their organisations had experienced financial constraints in areas such as: cuts in direct funding from local authorities; funding cuts from other government agencies such as the Department of Health (DH); and competition for non-statutory funding.

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This reflected the conclusions reached in literature review 2 (chapter 3) where the Deaf and Disabled People's Organisations (DDPOs) in the Inclusion London (2012) report and three of the DPULOs selected from outside of the London area had experienced financial constraints in similar areas.

Of the remaining CEOs, the CEO of E4 did not state that his/her organisation had experienced any financial constraints. However, although the CEOs of F3 and F4 indicated that although their organisations were not currently experiencing financial difficulties, they were still mindful of the impact of such constraints:

'... OK, inevitably making sure that we continue to be valued by funders in a difficult financial climate... we've been successful and the council and others still want to continue to invest and promise to continue to do so but it's a challenge because you've got to continually ensure that you are delivering in order to maintain their confidence in you. So, it's a challenge but we're being reasonably successful right now' (CEO, F3).

'I think at the moment the challenges that we face are that, not surprisingly, our local authority has announced again that they will be reducing contract values for the next financial year... our income streams at the moment are tied up to one department in the local authority... OK it's the department that spends the most money across the local authority but it's still primarily one department and that gives me concerns...' (CEO, F4).

In contrast, while the CEO of E2 did not mention the issue of financial constraints, it was suggested that his/her organisation might experience such financial problems in the future:

'... we have a massive contract with the PCT [primary care trust] and with that moving over to GP commissioning, we're not sure where we sit with that. We have a smaller contract with the local authority which is up for review but we're not too worried about that either. So, financially, we've got good reserves, so, if everything was to fold we'd have about 18 months operating funds.

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Our lottery project comes to an end next year but we've just been told we can go through to stage 2, so, that's hopeful and then we're developing the trading company. So, I wouldn't say we were too concerned about finance at the moment... it may not turn out in the long term but at the moment we're satisfied we're all doing as much as we can really and we've got some reserves cushioning' (CEO, E2).

While the CEO of E2 demonstrated that his/her organisation was currently operating a range of contracts and developing a trading company, these did not appear to offer any long-term financial stability because of their limited lifespan and uncertain future. This CEO also appeared to have an unhealthy reliance on the organisation's reserves and rather than offering a financial cushion, the use of these could result in failure. This concurred with evidence presented in literature review 2 (chapter 3) from three DPULOs that employed their financial reserves to support the operation of their organisations. These financial risks were highlighted by Gaskill et al. (1993) (see literature review 2 (chapter 3)) who stressed that similar practices could result in the failure and eventual closure of such organisations.

The CEO of E1 expanded on the impact of financial constraints and stated that they were the source of all the other challenges his/her organisation was facing:

'I have to be very very conscious about the fact that we have to make money in order to survive as an organisation in order to fulfil our vision and our mission... I think the challenges are mainly financial and all the other challenges arise or flow from that' (CEO, E1).

In contrast to the CEO of E1, the other CEOs did not specifically link financial constraints to the challenges their organisations were facing. However, along with the CEO of E1, they did highlight a range of other issues that might impact on their organisations' financial wellbeing. Such issues identified within the 12 transcripts are outlined in sections 6.3.3.2 to 6.3.3.4 below.

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6.3.3.2 Contract procurement

The majority of CEOs (7 of 12) indicated that their organisations had experienced challenges in the way that local authorities and other commissioners were managing contract procurement processes. For example:

'OK, so I suppose what we've seen is the movement from grant funding to contracts for services over the time I've been in post and so, the proportion of our income has changed considerably in terms that most of it is derived from contracts for services, 99% I think... a combination of block and spot... so, we've got block purchase for the direct payment support service that we run and we also run one in...in... then spot purchase, a mixture of spot purchase and individuals purchasing with a direct payment for the home support service... so, the environment has changed considerably and one of our concerns is about our direct payments service... our contract is nearly up... Basically, our contract has been rolled over for a number of years but at some point it will go out to tender. We keep being told every year that it's going out this year and then it doesn't happen which presents its own challenges' (CEO, E1).

The interview transcripts highlighted the struggle many of the DPULOs were facing having to operate in a competitive environment which they had little experience of in the past:

'I think the biggest challenge with contract services is when you're doing it on a yearly basis and that tends to be the local authority because they keep saying they're going to put it out to tender and then they leave it until the last minute, it doesn't happen and you're left with an extended contract.'

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I would prefer it to a degree if you're going to extend it by 12 months then give us three months' notice and tell us whether it's going to be extended or not rather than leaving it until a month before where you're chasing and trying to find out what is happening because often you've started the consultation with your staff by then and it could all be avoided if they were a bit better with the notice period or sort yourself out and put it out to tender and meet the timescales but a new thing we've had locally is where they just extend it for six months and then based on their monitoring report that you send back they decide whether they'll give you the second six months' (CEO, E5).

'... we're being increasingly asked to deliver more for nothing. So, for example, the housing broker, we've got the money to employ them but usually you pop a management fee in there to cover your costs to help you deliver things in the future... we're not getting any of that because there's just no money and we're being asked about: If you reduce that service there what's the implication? How much can you do for very little? I guess you're hearing this all the time in these interviews and it makes it a little bit boring hearing it... ' (CEO, F4).

The seven CEOs indicated that their organisations had experienced a range of challenges with the contract procurement processes undertaken by local authorities and other commissioners. These included: contract periods that were too short; the undefined award of contract extensions; lack of communication about contract notice periods; and attempts to reduce agreed service delivery or contract values. These issues presented the organisations with a lack of clarity and confusion over contract procurement processes.

Literature review 2 (chapter 3) demonstrated that the DDPOs included in the research undertaken by Inclusion London (2012) had experienced similar issues with contracts that were being awarded by local authorities and other commissioners. Further evidence of these problems was also provided by Williams (2014) who noted that DPULO in the south-east of England had experienced similar challenges.

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In contrast, although the CEO of E3 had not experienced problems with contract procurement processes, he/she highlighted the challenge of opposition from some DPULOs to contracted funds from disabled people being regarded as business opportunities:

'I think it's really important that people understand the language of surplus or profit and don't see that as a dirty word and I think that other DPULOs have struggled with that concept. The biggest challenge that I've had is from fellow DPULOs that believe that we've sold disability and disabled people down the river because we're making money out of them and I've always said that what we have to do is develop and deliver high quality services that people want to buy whether that's with their own money or from money that they get through a local authority ... ' (CEO, E3).

The quote from the CEO of E3 highlighted some of the tensions within the disability movement while making clear their own view that some other DPULOs needed to be more business-orientated when dealing with the funds for independent living services held by their disabled clients. In addition, the CEO appeared to suggest that there was a need to not only offer high quality services to disabled people who had received their money from local authorities but also to those who had funded their own independent living support.

6.3.3.3 Competition

A majority of the CEOs (7 of 12) indicated that they faced a key challenge during the contract procurement process through competition from national organisations. For example:

'... we're already starting to see that there's a slight move away from supporting local services to getting in bigger, cheaper national providers... we've still gone for contracts we've gone for services, to run services which we probably would have got a few years ago and in fact in one case did get a few years ago but didn't get this time because a large national organisation said we can do it and we can do it for cheaper and there's a move towards economy rather than quality of service... ' (CEO, M1).

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And

'... because recent tendering exercises in... and it's happening everywhere, means that they favour the larger organisations because the risk, both financial or mainly financial, the kind of contracts that we're seeing attached to tendering exercises means that the tendering organisation carries a lot of financial risk and that favours the larger balance sheets of bigger organisations... In a recent tendering exercise, we didn't go for, I think four out of the five winning tender organisations were national organisations. So, it's a worrying environment because of the budget pressures on local authorities... they are wanting to get the cheapest price possible, even when they say price isn't the only factor it's a very large factor for them' (CEO, E1).

'... the big challenge for us recently has been trying to ward off the big nationals coming in and taking over from the local voluntary organisations or the local ULO... I mean, we were quite surprised really when the contract came up for direct payments in April of this year that a lot were national disabled organisations and the local authority thinks that local ULOs like ours can't run services by intimating that we are not capable of providing the service that the big national organisations can and we have plenty of examples... locally around ULOs who have been taken over by bigger national organisations...' (CEO, F1).

The seven CEOs indicated that their organisations had experienced a significant level of competition from national organisations for local authority and other commissioned contracts. The CEOs believed that the reasons why national organisations were in an advantageous position when tendering for such contracts included: national organisations could operate contracts at a cheaper price; national organisations were better able to support the financial risk of high value contracts; and national organisations were able to operate contracts in a way that the commissioning agents believed to be more professional.

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Literature review 2 (chapter 3) demonstrated that in the research undertaken by Inclusion London (2012), DDPOs had experienced the challenge of competition from national disability organisations when tendering for contracts. In addition, Williams (2014) stated that some DPULOs in south-east England had lost major contracts to national, non-user-led organisations for similar reasons as those provided by the seven CEOs.

The CEOs of E2, E3 and F3 did not indicate whether their organisations had experienced competition from national organisations for local authority or other commissioned contracts.

In addition, the CEOs of E1 and F2 raised the dilemma of competing for such contracts with other ULOs:

*'Do we or do we not tender against other user-led organisations?
A really difficult question, difficult because if we don't and a national wins it we feel that's not the outcome that either organisation would have wanted. If we do, we feel compromised because we know that another user-led organisation that might not survive might be the consequence. It's a difficult position I think as we don't want to be a massive organisation winning all the contracts going. We're not ambitious in that sense but we would like to survive as a user-led organisation. So, it's a bit of a minefield' (CEO, E1).*

'... we've very much had to toil with that especially in the terms of where independent living support services have been over the last few years, you know... do we go into certain local authorities? Probably not because we know that the local ULO can deliver services as they are professional, you know? Do we not go into other local authorities because there's a ULO there? So, is it kind of better the devil you know rather than our organisation establishing itself in the area and working to keep out the likes of... and... Trust and... and... and organisations like that?' (CEO, F2).

The CEOs of E1 and F2 claimed that they would only tender for contracts against other ULOs in the event that national organisations were also involved in the same commissioning processes

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These two CEOs indicated that the main reason for tendering against other ULOs was to try to stop national organisations from winning such contracts.

6.3.3.4 Capacity

Half of the CEOs indicated that a lack of capacity was a particular challenge for their organisation:

'Challenges, gosh. I think our biggest challenge is capacity and time, probably the same really in that there is a lot happening and there are too few of us to be everywhere we need to be. That's the big challenge... it's about capacity and time and about being able to position ourselves to be in the right place really... we have people that have decreased hours and things like that which is why the big issue for us I think is capacity and time to do things... because our management has decreased by, I think, it's 80%... So, in terms of management, there's... and I, we've lost our middle layer of management...' (CEO, E2).

For others the importance of building capacity within the organisation was emphasised:

'Well, I think it's about capacity and building capacity and that's about getting the resources to staff the organisation in order to do all that's possible and I'm one of those that always wants to do more and more. So, it's about that capacity but it's also about building the capacity of the board and the membership really in order to develop more people who are willing and able to contribute in so many different ways. So, what you need to do is to support people with training and development and other support in order to make an effective contribution...'

The same CEO highlighted an interesting point in that many disability activists were now in full-time employment. While this was an important part of inclusion, it meant that the CEO no longer had so much capacity within his/her organisation:

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I think it's more difficult to find the people who are rooted in the disability movement because they are now working full time and therefore, don't have that capacity to be influential really. You know, we've got seats at the table of select committees and the adult social care board and things but it's often myself with another board member and we need more capacity, we need more people but that's a challenge. My challenge is having the time to get out what I have to do in my day-to-day role to take part in these other things' (CEO, F3).

Both CEOs highlighted the problem of not having sufficient numbers of employees required to operate productive and efficient organisations. While the CEO of E2 had earlier stated that his/her organisation had not experienced any financial constraints, this would appear to have been incorrect as he/she also stated that it had been necessary to reduce staff hours and that the middle level of management had been lost. The capacity issues that this CEO mentioned could therefore be related to financial challenges that the organisation faced.

Similarly, the CEO of F3 also stated that his/her organisation was not facing any current financial constraints. However, capacity and capacity building was an issue in two areas. Firstly, his/her comment about the building of capacity appeared to suggest that the organisation had a particular issue with having sufficient finances to employ more staff. Secondly, the CEO indicated that it was difficult to identify potential recruits with the relevant necessary experience within the disability movement.

The CEO of M2 directly linked capacity issues to the financial constraints his/her organisation faced:

'... another challenge is the funding, in a way it's like a catch 22 because we've got so little resources now, so for example, I had to go down to two days a week when we lost the funding but I do have Eileen who's the general manager and does the day-to-day management but for me doing all the board development and the strategic funding, I can't do all that in two days, it's impossible really. I've been putting a lot of my own time into it you know...' (CEO, M2).

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It would appear that in the case of M2 the day-to-day operation of the organisation was adequately functioning. However, the reduced availability of the CEO through funding cuts had resulted in a lack of strategic management capacity and potential future problems in the viability of the organisation.

In contrast to these three CEOs, the CEOs of M3, E5 and F1 appeared to suggest that their organisations suffered from capacity problems but from the analysis of the transcripts this could not be directly or indirectly related to financial challenges:

'For example, the... has been commissioning small pieces of work, quite rightly they've been commissioning disabled people's organisations to deliver that. So, they wanted somebody to write about... but they are all for very small amounts of money, equal to about £5,000 or £6,000 and for a small organisation that proves very difficult. I mean, you can't actually put in for management costs. Bigger organisations, you could sort of give that piece of work to another member of staff and they could do it, write a report about... but for us, we'd have to think about... Have we got the capacity to house somebody? Who's going to do the recruitment? It's another responsibility for our team leader to manage yet another member of staff for like a 12-month or an 18-month contract...' (CEO, M3).

'One of our shortfalls if you like in terms of a challenge is capacity to do more around the campaigning aspects, without a doubt. I'd love to, it's really important but that ultimately has to be absorbed by one of the senior management team and depending on the pressures of the amount of board papers we've got for any given month, something's got to give. You can't absorb it all' (CEO, E5).

'... to be honest I think we have actually been kind of overwhelmed this past 12 months in trying to get this.... And we've kind of like...we've let a lot of stuff kind of slide maybe that we shouldn't have...' (CEO, F1).

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Literature review 2 (chapter 3) demonstrated that the comments made by the six CEOs reflected one of the issues raised in research undertaken by Williams (2014) where some south-east England DPULOs did not possess the capacity to complete contract bidding processes satisfactorily. However, more fundamental issues are raised about how the pressures on the CEOs in DPULOs also affected their ability to undertake aspects that at one time would have been seen as the backbone of the disability movement such as campaigning for the rights of disabled people.

6.3.3.5 Board/staff recruitment and retention

In response to questions concerning the challenges faced by their organisations, half of the CEOs stated that they had experienced related problems with the recruitment and retention of appropriate people on their boards. The comments by the CEOs below indicated that there were issues with the recruitment and retention of board members. These included: difficulty in recruiting disabled people who were available to serve; difficulty in the recruitment of qualified and experienced people, whether disabled or not; difficulties with travel to undertake board activities; and lack of commitment and availability once appointed.

For example:

'I've also identified a lot of issues for the board like there's no succession planning and there's no treasurer but if the chair suddenly disappeared tomorrow it would be a real worry about what would happen. We do have two vice-chairs but they both work full time and the chair does as well but it has concerned me that there needs to be more trustee availability. We also made a mistake the other year... we took on anyone. We had a couple of people but they didn't last the course... we did have one person that was very good but he stood down because he was young and he got overwhelmed...' (CEO, M2).

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'... although we have a good board now, it's always a struggle to find disabled people willing to sit on the board... I think there's some apathy there if I'm honest and I think it's also about being in a county... we're not a particularly huge county but travel can be an issue for disabled people and if you haven't got your own transport in... it's a nightmare because public transport is rubbish' (CEO, E1).

'... it's an issue isn't it really? I think about ensuring you've got disabled people on the board... Our honorary treasurer actually rather than the finance officer is a non-disabled person, they, the board, appoint each year but my preference would be for a disabled person but that's not easy' (CEO, F3).

An example of the difficulty in recruiting suitably qualified disabled people was alluded to by the CEO of E3 who instigated the establishment of a subsidiary trading company to the organisation. The board of this company was a new direction for DPULOs as they included newly recruited non-disabled people who had experience of impairment and the relevant necessary skills that were not available within the main board of trustees/directors:

'I think the real challenge has been to retain 100% of the board with self-declared impairment but find those individuals who have a track record in business and strategic acumen and having a board for the trading company has enabled us to look at non-executives who have experience of disability but not an impairment themselves in order for us to bring in, in the short term, those skill-sets that were hitherto missing. Our long-term aim is to have on the board of director's subsidiary 100% disabled people as well as on the main board which will always remain as 100% disabled people' (CEO, E3).

Half of the CEOs indicated that they had experienced problems with the recruitment of suitable disabled people for staff positions within their organisations. Examples of quotes from the CEOs were illuminating and potentially reflected a shift in expectations and attitudes by some disabled people who may seek inclusion in mainstream organisations rather than in an organisation focussed around disability support.

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This may reflect generational differences between those who have been part of the disability movement since its inception who fought for the establishment of DPULOs, and those who have grown up with these organisations in place. For example:

'That's another challenge for us. I think out of 22 I think we've only got four disabled staff members. So, that is a big challenge and I think it's a challenge because you've got two aspects here. First, disabled people might not want to work in a disabled people's user-led organisation because they want to get away from disability and second, they don't fit the profile of who we are looking for or they can't do the jobs that are asked for in the posts we advertise' (CEO, E1).

'One area in which we're very weak. We have 14 staff now and we've been up to 25 at different times but I think out of 14 we've got three of us who have a recognised disability: two with a visual impairment, one of them is going to a good job with the RNIB [Royal National Institute of Blind People] and me. However, we've struggled mainly because I think... is a very rural county. I think the profile for a young disabled person is that you go to school, you go to college and you go to university but you don't come back and I think for young disabled people that's even more so because you go into Birmingham, Manchester, whatever because you've got accessible buses and things going on why would you want to come back to rural old... where you know there are accessible buses running through the main cities in the counties but if you're any more than 10 yards off of those you're stuck' (CEO, F2).

'It's been really interesting. We've been out to recruit recently for five new roles and we've got a couple coming on board later in the autumn and of those five... no, let me talk about four at the moment because we were very surprised because people had the opportunity to say if they had any particular access needs at interview or for their role going forward and then declare separately on the monitoring form if they identified as having an impairment... very few people did.

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So, I don't know if it's about how we've recruited for people this time round or what's going on in the job market but I'd expected it to be much higher in terms of numbers of applicants with impairments' (CEO, F4).

The comments by the five CEOs indicated that the challenges with the recruitment of disabled people to fill staff positions included: inadequate or unsuitable qualifications and/or experience; perception, particularly by younger disabled people, that there was a wider range of opportunities elsewhere; and insufficient numbers of disabled applicants.

However, the CEO of E2 appeared to take a pragmatic approach to the recruitment of disabled people into his/her organisation:

'... we always appoint the best person for the job irrespective of anything but our recruitment does say disabled people with the minimum specification or whatever the terminology is they will be interviewed. We do all the usual but at the end of the day it's the best person for the job' (CEO, E2).

All six CEOs indicated that there were no major barriers to the recruitment of non-disabled people into their organisations. However, the CEO of E2 appeared to suggest that those organisations who were perceived to not recruit disabled people might be seen in a negative light by others in the disability movement:

'... I think it's around about the same... Yes, the same as the board about 75%... but I would say that a lot of us have hidden impairments... but it does to some people because they don't see you as a DPULO which does cause us some anxiety some of the time though. We don't want to be going around with labels on our backs saying we've got 'X', 'Y' and 'Z' you know' (CEO, E2).

The comment by the CEO of E2 appeared to suggest that disability activists might claim that his/her organisation was not actively recruiting disabled people and therefore had not fulfilled one of the ODI criteria to be considered as a DPULO (ODI, 2011, cited in Bott, Sweeny and Watts, 2013).

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However, the CEO refuted this view by confirming that his/her organisation employed approximately 75% disabled people as staff. The CEO also felt that his/her staff should not need to advertise the nature of their impairments in order to be described as disabled people.

6.3.3.6 Board/staff skills

The CEOs were not specifically questioned about the skills that were lacking in their organisation. However, half indicated that both their trustees/directors and/or staff lacked a range of professional and business skills such as marketing, governance and accountancy.

For example:

'We buy in skills and resources we don't have and the knowledge we don't have... we buy in HR support, IT support and that kind of thing' (CEO, E1).

'We've bought in on a secondment from DWP [Department for Work and Pensions] one of their high-flying fast-streamers who has come in and has been able to develop the voice side of the business which has also been really important because that's what... was originally set up to do and that's where our central objective is' (CEO, E3).

In addition, the CEO of E5 intimated that there was a financial benefit to his/her organisation if the professional skills were held at director/trustee level rather than through the recruitment of an additional salaried employee:

'What I can tell you now on our board is we've got a gap in marketing... we've got a marketing sub-committee and we've got some very willing staff who are actually very good with previous jobs where they bring in around the table a range of skills and that's great as a kind of fill-in for the gap and for moving forward... so, that will be another way until we've got a skilled disabled person in marketing on the board then at least we will have a corporate organisation and that will be very big in terms of looking at marketing and looking at our leaflets and that time is donated free' (CEO, E5).

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'Well, I suppose we're part way through achieving that in that, you know, with... earlier in the year we've done sort of a skills audit of the board and then we're planning training which we have lined up a disabled trainer to come and do work on governance and all that but it's not happened yet but it's clear to me that that working with the... that we would benefit from having input from others, you know, other disabled people are much more able to give people the skills and confidence to go forward than a non-disabled person is' (CEO, F3).

'... and we need to do more work in terms of looking at the diversification of our board and the diversification of some of the skills on our board. Our board of trustees is what it is because the people that self-identified at the time were fully engaged in this organisation and there's never been, since that point, any real due diligent process around the skills that are needed or where they fit. So, for example I know that we're looking for somebody with accountancy skills to come on our board... We outsource to an HR and legal organisation. So, for example, one of my staff recently has put in a request as they've moved out of... and out of the region put in a request for part-time working and I worked with our HR advisor to move through that process. So, for something like that we gather assistance from the people from the company that we retain for those services and we use that professional services company to do that kind of stuff. They've also helped us with policies and when we've got a problem and I've asked how do we deal with this? Also, I worked with them when the staff were TUPE'd [Transfer of Undertakings Protection of Employment] over and we had to revise contracts and to make sure under TUPE legislation everything was legal' (CEO, F4).

The CEOs of E1, E3 and F3 recognised the need to acquire individuals with professional and business skills on a non-permanent basis to provide the knowledge that their own organisations did not possess. In addition, the CEO of F3 appeared to be interested in obtaining the support of people with the lived experience of disability rather than those with only professional and business skills to provide training within his/her organisation. Such a comment implied that the lived experience of disability was a vital component in understanding the needs of disabled people.

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6.3.4 Future opportunities for DPULOs

The intention of this section was to highlight the future opportunities for DPULOs from the perspectives of the CEOs involved in this research. The CEOs outlined a range of potential opportunities that were emerging in spite of the financial constraints and challenges of securing contracts outlined earlier in this chapter. The data revealed not only opportunities to extend traditional independent living services through the introduction of personal health budgets but also new ways of thinking about the role of the organisations, relationships between DPULOs and between DPULOs and the wider community. However, the repeated theme of upholding core values at the heart of their organisations and finding new ways to survive were also apparent for some DPULOs.

6.3.4.1 Traditional independent living services

In questions concerning future opportunities, half of the CEOs indicated that their organisations had plans to introduce and/or extend the range of traditional independent living services they offered to clients. In addition, some of the CEOs detailed opportunities that were emerging from the targets being set for local authorities regarding the numbers of people that were being moved onto personal budgets. For example:

'I think the biggest opportunity is for our trading company, so, around the personalisation agenda in that if the local authority have to get 'X' number of people onto personal budgets and of those that are on personal budgets another high percentage have to take direct payments there are clearly opportunities there for us to offer things like managed accounts, payroll and the other things we've already been talking about... we're also setting up a personal assistant register that's being designed at the moment. So, we're seeing a lot of opportunities there, opportunities around support planning'
(CEO, E2).

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And services required to offer reablement support:

'So, a really good example is services that provide reablement to disabled and older people... they deal with thousands of disabled people and the key to that is keeping them out of GPs' surgeries and hospitals and that's when places like... can come in and offer a range of services for self-help and peer support to individuals once they've had their initial treatment. So, I think that is probably the biggest opportunity for us in terms of broadening the number of people that we can offer services to... I think most DPULOs have thrived on traditional direct payments and social care. That is going to happen in health, at what speed I'm not sure but it will happen and if you are able to provide a service similar to social care for health then that opens up a massive market.'

The same CEO also sees opportunities for providing peer support in relation to new policy initiatives in employment and education:

Likewise, with the revision of Access to Work which is the disability employment flagship programme and the opportunities for DPULOs to play a role in supporting, through peer support, disabled people in that service as well. So, I think there are real opportunities in social care in terms of reaching out to the wider market in health reaching out to the existing market who have health and social care support and a new market, particularly those with long-term health conditions through personal health budgets, employment for disabled people who are employed and have disability entitlement, whether that's Work Choice or Access To Work and probably education as well and by definition you can extend that if universal credit comes in and disabled people get one pot of money for everything, then you should be able to extend that to transport, leisure and all other services' (CEO, E3).

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Some DPULOs had sympathetic local authorities who still valued services based on direct experience:

'The council now recognises the importance of seeking more user-led organisations to deliver services for people, so, there is a lot of capacity to do that and to bid for new work and in particular the recognition of the importance of providing universal services, not just for people who meet social care criteria. So, we're getting an expansion of advocacy for all disabled people. We're now trying to persuade them to invest significantly in welfare benefits advice and they've understood the importance of that being delivered by a user-led organisation. So, there's about half a million over the next three years coming up on that which is really good' (CEO, M3).

The CEOs demonstrated that the introduction and/or extension of traditional independent living services were believed to represent future opportunities for their organisations. The range of services highlighted by the six CEOs included: managed accounts; support planning; payroll; welfare rights advice; advocacy; personal health budgets; and Access to Work. These services were characteristic of those already offered by organisations involved in this research.

As outlined in literature review 2 (chapter 3), both the Improving the Life Chances of Disabled People policy document (PMSU, 2005) and the outcomes of research undertaken by Maynard Campbell, Maynard and Winchcombe (2007) indicated that such services were vital for disabled people to have the chance to achieve independence, choice and control over their lives (UPIAS, 1976; Barnes, 2007).

In contrast, the CEO of E5 felt that his/her organisation was currently consolidating its position regarding independent living services. However, the CEO also indicated that any future opportunities were dependent on feedback from his/her organisations' constituents:

'I think the opportunities are continuing what we do now but for me the answer to that question would depend on what our local disabled people tell us what they want and need.'

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We're here to plug gaps and we're here to deliver information and advice and the support services that achieve our mission and enable disabled people to live independently, have choice and control and remove barriers that exist in society. So, it would very much depend on what they tell us what they want and need and I will do my best, whether that be through piloting charged-for services to be able to then look at rolling it out when you've got a good argument for the board that it's worked or whether that is finding a funding pot we can look at getting a contract to deliver something around it or maybe a bit of both but I do think that would depend. Right now I'm perfectly happy that the feedback we've had is people have got what they need right now to be able to achieve what they want for their individual outcomes, so, I guess it's for me about delivering what we do now but delivering that in the best way we can and almost consolidating' (CEO, E5).

The CEO of E5 demonstrated that his/her organisation was committed to the continuing support of local disabled people through the delivery of independent living services. The CEO indicated that these services provided his/her organisation with a range of opportunities. These included: the provision of such services in the best way possible; the consolidation of such services; and feedback from his/her constituents concerning the need for new services. The introduction of these services fulfilled the recommendations in research undertaken by Maynard Campbell, Maynard and Winchcombe (2007) (see literature review 2 (chapter 3)). In contrast to the other five CEOs, the CEO of E5 alluded to some sources of funding that might support the introduction and/or operation of future services. These included: piloting charged-for services; the identification of funding through contract procurement; and a combination of these two funding sources.

However, in spite of an investigation during the course of literature review 2 (chapter 3) into the Strengthening DPULOs Programme (DPULO Programme Team, 2016), not one of the six CEOs indicated whether their organisations had made an application to the programme for funding to support the introduction of new services.

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6.3.4.2 Innovative independent living services

The majority of the CEOs (8 of 12) presented ideas for a range of innovative support services that they believed would represent future opportunities for their organisation, particularly in relation to the use of new technologies. For example:

'I suppose one of the new kind of areas that I'm thinking proactively about is the use of technology... as we increasingly do use ICT in all sorts of ways and that's one of them... I was thinking more about assistive technology in relation to disabled people and their needs... part of the issue is disabled people having access to equipment and support which I'm also very interested in' (CEO, E1).

'... we're looking at offering services like for example, going into somebody's home with a laptop, somebody that might not have the internet and a dongle and helping them to find cheap insurance, those sorts of things, we're looking at offering and a lot of organisations, they don't do that' (CEO, E2).

As well as these enabling services one CEO in particular highlighted the importance of making sure these 'new' services did not create dependency amongst disabled people but rather built on their existing strengths and capabilities – highlighting peer support as particularly important:

'... it's all about, as far as I'm concerned, people being self-sufficient in what they do and what we are saying as an organisation and as a ULO... what we don't want is for people to become dependent on us and to move away from the local authority because to become dependent on us is not giving people any kind of self-sufficiency or anything but what we want to do is to actually skill people to do it for themselves. So, we're kind of looking at a whole training programme of how we can develop training for people to become good employers, not just employers but around building skills training and because a lot of people that we work with, especially within peer support have fantastic skills that they don't even realise they have got... and it's about kind of what you want people to get them to recognise those skills and to be able to support each other...

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within the peer support group and it's just kind of working more on that for people to be reassured and to have the confidence that actually they can do this themselves without becoming reliant on us or anybody else really' (CEO, F1).

A further CEO raised the importance of new directions that integrated services into the mainstream and gave disabled people visibility for their work, as well as offering opportunities for DPULOs to work in partnership:

'... Citizen's hubs, which is a concept we developed two years ago. So, each borough within the county, which there are 11 having at least one visible high-street shop location run by disabled people providing information and access to advice and advocacy and support. So, promoting inclusion of disabled people in communities but also providing a visible point of access for information and support and there's a considerable amount of money going into that and there's three user-led organisations that are running that as a partnership, doing bits of it together in order to deliver the services. So, there's lots of opportunities there' (CEO, F3).

Of these eight CEOs, six indicated that their organisations planned to introduce innovative support services in the future. These included: access to and support in the use of assistive technology; skills training; citizens hubs providing information, advice and advocacy for disabled people; and support with finding cheap online products for people with no access to the internet. However, although these initiatives represented novel methods of providing support services for disabled people, the CEOs failed to mention sources of funding to help their organisations introduce such services. This included the Strengthening DPULOs Programme that was launched by the coalition government of Conservatives and Liberal Democrats in 2011 (DPULO Programme Team, 2016) (see literature review 2 (chapter 3)).

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In contrast, the CEOs of M3 and F4 pointed out that the innovative support services that they had identified would be used to generate income for their organisations:

'Well, I suppose trying to maximise opportunities for income generation. So, like the transcription service and generating income for the consultations, disability equality training for local authorities once we get out of the current economic climate and now that local authorities don't have any access officers or equality officers and they are lacking in that sort of knowledge I think that there's a need for those services and also, we've learned through trial and error that we need to charge for our services and to make that work will be beneficial to us. It's not just about accounting for our time, it's about making a profit out of that time as well' (CEO, M3).

'We'll also look to develop new business activities. I'll be honest with you, I'm not comfortable about the phrase social enterprise because I don't think it actually makes people focus on the fact that it's business and a charity is a business and if you've got less income than you've got expenditure then you're not going to be sustainable for very long and it's for me about making this organisation more business focused as we move forward... we've just kind of started to make some real inroads into new areas of work which we've never previously considered and now we're looking at what are the new areas of work and how do we fund those. For example, we're currently looking at business opportunities around food and training to provide some opportunities where we may not have considered before. So, café services, sandwich rounds or whatever it is and how we can provide a fully-hosted service which includes our training facilities' (CEO, F4).

The CEOs of M3 and F4 identified a range of innovative support services that included: the further development of a transcription service; a consultation service; disability equality training; café services; sandwich rounds; and training to provide catering services. These innovative services were not only available to disabled people but also appeared to have been specifically designed to support the whole community.

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These two CEOs aimed to generate income for their organisations by developing new services and replacing those services that had previously been withdrawn from, for instance, local authorities.

6.3.4.3 Partnership working

Given the earlier finding that austerity was breeding a climate which potentially put DPULOs in competition with each other as well as with large national organisations half of the CEOs indicated that they had considered partnership working to be a future opportunity for their organisation. For example:

'Opportunities... the Police were really impressed when they did work with us and when I go to the... meetings the DPULOs are really impressed about the opportunity to get together and we're looking at doing a consortium bid at the moment... there is interest from, you know, like local authorities and I mean you've got the health and wellbeing people coming out. I mean, there's a lot of... things are really changing and you've seen a real sea change across the country and I think there's a lot of opportunities there but you need to be strong, you need to be able to plan ahead... you know, I was talking about a consortium... on Tuesday I said it would be a good idea if we could get together in a consortium before a funding opportunity comes-up so that you've got everything in place and then you can take advantage... of the funding but I do think this is an exciting time' (CEO, M2).

And interestingly, thinking about the various strengths different DPULOs could offer to a partnership:

'So, I think that's a real opportunity, opportunities to build strategic partnerships and joint ventures which is why having a subsidiary company is so important because I think a real opportunity is for... to have pieces of different pies, not necessarily wholly owned by... but maybe in joint venture or partnership with other organisations which reaches out to a much wider number of disabled people' (CEO, E3).

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'... the model we've been talking about and looking at is that thing where we might come-in and have a bigger share for one part of a contract or we'll deliver one element... with the aim that in 3 or 5 years time at the end of the contract that we take a different approach that they could be the lead partner and go for it and we can support a consultant going-in on a monthly basis to support the CEO for example... we've looked at that model a couple of times' (CEO, F2).

The six CEOs believed that partnership working would prove to be an important future opportunity for their organisations in areas such as: helping to improve planning; improving access to the tendering process with local authorities and other contractors; giving them access to larger numbers of disabled people; providing an opportunity to support other organisations; and enabling them to generate income.

The comments from the six CEOs demonstrated that they understood the benefits of working in mutual partnerships with other organisations in order to achieve their overall organisational objectives.

In literature review 2 (chapter 3), Bott, Sweeny and Watts (2013) investigated the key structural characteristics of ULOs. The partnerships described by the six CEOs appeared to be commensurate with models such as those consisting of formal partnerships between two or more organisations; and hub and spoke models where a number of organisations contribute to the ULO at the centre (Bott, Sweeny and Watts, 2013).

6.4 Summary

In this chapter, I outlined the 12 CEOs accounts of the origins, growth and development of their organisations together with their structures and activities. The particular challenges that currently face these CEOs have also been provided. Some common themes have emerged across these areas.

All of the 12 DPULOs shared common and deeply held values, namely: independent living; choice and control; equality; inclusion; and the adoption of the social model of disability.

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The origins of all the organisations involved in the stage 1 research were based within the wider disability movement and were a unique part of the third sector, alongside other ULOs, in that the knowledge base that underpinned these organisations was founded on direct experience of impairment and being disabled by the structures and attitudes that exist within society. This experiential knowledge was at both the individual and collective level within the organisations and thus, the value of peer support was regularly highlighted.

However, the historical period, social and economic conditions under which the organisations developed had a significant impact on the way in which they shape their core activities and understanding of what it means to be a DPULO. For example, the organisations designated as mature (M) were established in a period where a number of social movements developed and as such, they had campaigning at their heart. This campaigning ethos continued to be held as a deeply important principle for these organisations. This in turn affected their relationship with local authorities and shaped their response to the marketisation of the state sector. More recently established organisations (E and F) have developed in a different historical period and their narratives generally reflect both the progress that has been made in terms of increased equality for disabled people and their comparative acceptance of the commercial activities that economic policies have required of them as local authorities have seen their budgets shrink. These differences were also reflected in the way in which activities and services provided by DPULOs evolved. For example, the mature DPULOs tending to opt for transcription services for their disabled clients and more recently, forming organisation developing services not only for disabled people but also for the wider community.

However, all of the organisations were subject to the impact of austerity measures, highlighting the fragile nature of the fluidity of power relationships between local authorities and DPULOs. In the earlier narratives, the shift from organisations being established by non-disabled people had an impact on, and was enhanced by, enabling policies and attitudes at local authority level and in particular, the valuing of experiential knowledge. As budgets have been squeezed and 'value for money' policies introduced, some local authorities have started to favour large national organisations at the expense of local DPULOs. This has placed DPULOs in a reactive position concerning the procurement of contracts. This has resulted in competition between rival DPULOs.

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Therefore, at different points in time it can be seen that DPULOs (along with the wider service user movement) have both shaped and responded to policy practices.

Currently, DPULOs find themselves in a position of having to adopt a profit philosophy and discover ways in which to raise money to augment their funding from the statutory sector. This has raised issues around the skill base and capacity of DPULOs. There are also clear tensions between DPULOs in retaining their core values and of finding a sustainable way forward. This in turn raises a more fundamental question about what it is to be a DPULO in the current financial climate with diverse views amongst their CEOs as to the need, acceptability and role of other forms of expertise in their organisations. For example, the co-production and delivery of services with family members, carers and/or non-disabled professionals who might be able to bring new knowledge and skills into the marketised environment.

In the next chapter, the findings from the semi-structured interviews will be used to design and implement the stage 2 survey.

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CHAPTER 7: FINDINGS 2 – SURVEY

7.1 Introduction

In the last chapter, the findings from the stage 1 semi-structured interviews of 12 CEOs from disabled people's user-led organisations (DPULOs) were presented. The findings were divided into sections that were commensurate with the three research questions for this study. An analysis of the semi-structured interviews was supported by a selected sample of the passages of text from the 12 CEOs. An analytical summary of the main findings was provided to support navigation within the chapter. The findings from this stage of the research were used to support the design of the stage 2 survey.

In this chapter, the findings from the semi-structured interviews will be used to design and implement the stage 2 survey. The survey findings will be presented using both graphical and tabulated results. These results will be accompanied by an analysis of the main findings from the survey.

7.2 Background

In the stage 1 research, semi-structured interviews with the CEOs of 12 DPULOs were undertaken such that the CEOs were encouraged to openly discuss a range of perspectives regarding their organisations. In chapter 6, an analysis of the research transcripts was provided. While a wide range of perspectives were discussed during the interviews, six key challenges were identified through the analysis process: financial constraints; contract procurement; capacity; competition; board/staff recruitment and retention; and board/staff skills. The analysis also identified three key opportunities: traditional independent living services; innovative independent living services; and partnership working.

As discussed in chapter 4, Mertens (2007) suggested that the use of one method to investigate a research problem could, in her view, produce misleading results.

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In addition, Mertens (2007) claimed that she designed her research methodology to ensure that the data collected reflected the true reality of human experience. Mertens (2007) believed that, within the transformative paradigm, a mixed methods approach that allowed for the collection of both qualitative and quantitative data was appropriate.

While the semi-structured interviews provided much detailed, rich and in-depth data, the sample was limited to the 12 organisations that responded to the initial invitation to take part in stage 1 of the research. Therefore, to further investigate the findings from the analysis of the semi-structured interviews, the research was extended to include a much wider sample of DPULOs. Consequently, a survey, designed to collect both quantitative and qualitative data was incorporated into the research design (Mertens, 2007, 2012).

The primary intention of the survey was to further investigate the six key challenges identified in the stage 1 research with a wider range of DPULOs. The design of the survey questions was informed by: the two literature review chapters; the stage 1 research findings; my lived experience as a disabled person; my experience as a trustee of a DPULO; and my full membership of a DPULO. However, the survey was also formulated such that the respondents were able to provide feedback on findings from the stage 1 transcript analysis that would enhance the research outcomes, including: ethical considerations; operational structures; relationships with commercial enterprises; and future opportunities. The survey was constructed using a total of 21 questions that reflected these required outcomes.

7.3 Selecting an appropriate survey software tool

As outlined in chapter 4, the survey results were collected using the internet-based tool SurveyMonkey¹ (SurveyMonkey Inc., 2018). As a blind researcher, I always had to be aware of issues related to accessibility, therefore, I was mindful to use a survey software tool with which I was familiar. Having used SurveyMonkey (SurveyMonkey Inc., 2018) in a previous research project (see: Carey et al., 2013)

¹ Note that SurveyMonkey is no longer used by ARU due to ethical concerns, however, at the time of the survey construction it was considered to be an appropriate tool.

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I felt that, while not fully accessible, it would be appropriate for the aims of the stage 2 research. In addition, at the time of constructing the survey, SurveyMonkey (SurveyMonkey Inc., 2018) was freely available to staff and students undertaking research at ARU.

The University of Reading (2001, p.18), when discussing survey responses, claimed that 'The most straightforward form of analysis, and one that often supplies much of the basic information need, is to tabulate results, question by question, as 'one-way tables''. I considered that such an approach using a narrative analysis was appropriate for this research (The University of Reading, 2001; SurveyMonkey Inc., 2018). I also felt that the survey analysis tools within the SurveyMonkey (SurveyMonkey Inc., 2018) application fulfilled such requirements. In addition, as my intention was to investigate if the stage 1 findings were reflected in the survey results, I considered that this form of analysis would achieve the required research outcomes. As Mertens (2007) suggested, such a process was used to demonstrate the credibility of my stage 1 research findings.

7.4 The survey response rate

As discussed in chapter 5, the survey was distributed by an independent gatekeeper, who was a senior executive from within the Office for Disability Issues (ODI) Strengthening DPULOs Programme. This senior executive was responsible for the construction and maintenance of a UK-wide database of DPULOs and similar organisations. This database included details of all organisations that the senior executive believed to be active in the UK at the time and could therefore be considered to represent the total population for the purposes of this research.

The senior executive sent a personal introduction, which included my participant letter and an internet link to the ARU online SurveyMonkey website (SurveyMonkey Inc., 2018), to all organisations included in the database. This represented a total of 340 DPULOs (n=340) (Bott, Sweeny and Watts, 2013). However, I did not have direct access to the ODI's database of DPULOs. Therefore, I did not know if the 12 DPULOs involved in the stage 1 semi-structured interviews were included or not in the total population of the 340 DPULOs. The personal introduction from the senior executive and participant letter stressed that the survey should only be completed by the CEO of the organisation to which the request was sent.

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A firm cut-off date by which the survey had to be completed was also included.

A total of 133 responses were received by the time the survey closed in June 2014. This represented a response rate of 39.2%. This figure compares favourably with Nulty (2008) who noted that in eight examples of online surveys, there was an average response rate of 33%.

7.5 Survey findings

As detailed earlier in this chapter, I have presented my survey findings sequentially by each question. The findings are divided into three main areas: The origin, structure and characteristics of DPULOs; income; and the core challenges faced by DPULOs. The analysis of the survey data indicated that there were some recurrent themes in relation to the core value base of DPULOs. These included: the disproportionate impact of austerity on the activities of such organisations; and the constraints surrounding the current ODI criterion for a DPULO.

7.5.1 The origin, structure and characteristics of DPULOs

Question 1. When was your organisation established as a DPULO?

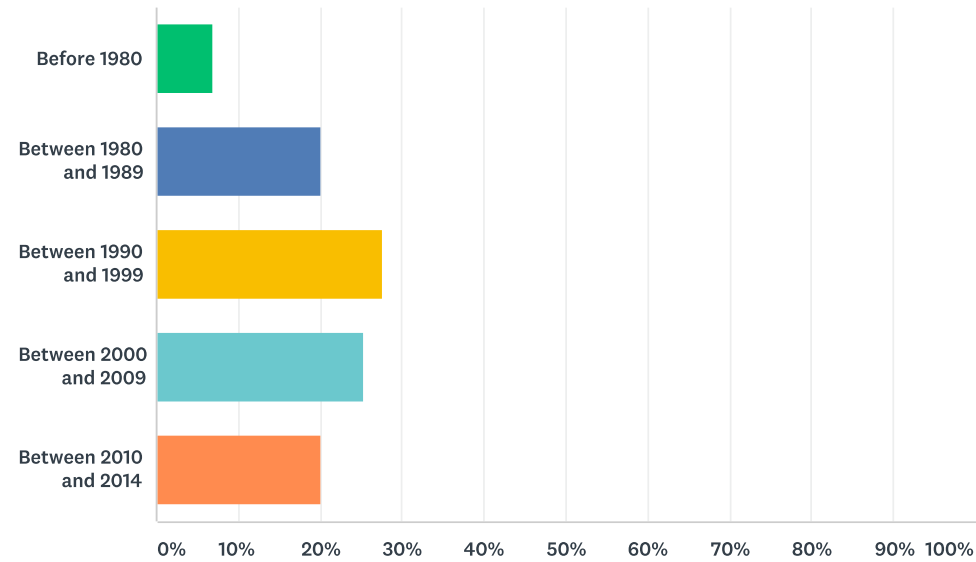
The 12 DPULOs that were involved in the stage 1 research were selected such that their establishment dates covered the period between the years of 1980 and 2009 inclusive. In addition, the DPULOs were selected such that there were representatives in each of the ten-year periods between 1980 and 2009. As I was concerned that that these 12 DPULOs might not have fully represented the population of DPULOs as far as establishment date was concerned the intention of survey question 1 was to better understand the establishment dates of the wider population. The CEOs were asked to select one of five ranges in which their organisations had been established. A total of 130 of 133 CEOs responded to this question and their responses are shown in figure 8.

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The responses demonstrated that DPULOs were established over the period of 1980 to 2009 inclusive as were the 12 involved in the stage 1 research. However, interestingly the survey also indicated that a relatively small number (nine responses) were established prior to 1980 and a significant number (26 responses) were established in the shorter period after 2009 to the closure of the survey in June 2014. In addition, the responses showed that there was a major expansion in the establishment of DPULOs in the period 1980 onwards. This suggested that in spite of the economic and political pressures they have faced, the number of DPULOs have steadily increased since their inception in the late 1970s.

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Answered: 130 Skipped: 3



ANSWER CHOICES	RESPONSES	
Before 1980	6.92%	9
Between 1980 and 1989	20.00%	26
Between 1990 and 1999	27.69%	36
Between 2000 and 2009	25.38%	33
Between 2010 and 2014	20.00%	26
TOTAL		130

Figure 8: Distribution of responses to survey question 1: When was your organisation established as a DPULO?

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Question 2. In what area of the UK is your organisation located?

The 12 DPULOs that were involved in the stage 1 research were selected based on their date of establishment: their location within the UK was not considered to be a criterion for selection. Consequentially, in the design of the survey questions, it was considered that these 12 DPULOs might not have fully represented the population as far as their location within the UK was concerned. However, I felt that it was important to discover if the organisations involved in this stage of the research were located in all parts of the UK.

Therefore, in question 2 the CEOs were asked to select one of 10 geographic areas within the UK in which they felt their organisations were located. A total of 129 of 133 CEOs responded to this question and their responses are detailed in figure 9.

In the stage 1 research, all 12 of the DPULOs were located within English geographical areas. The responses to the survey demonstrated that DPULOs were located across all regions of England as well as all countries of the UK. The majority of responses were from counties in the North of England. However, the number of responses from Northern Ireland and Wales (one and two responses respectively) were considerably less than those from the other geographic areas. I was aware that there were different funding arrangements within the countries of the UK and this might have had an impact on the distribution of responses in question 2. However, discussion of such funding arrangements was beyond the scope of this research.

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Answered: 129 Skipped: 4

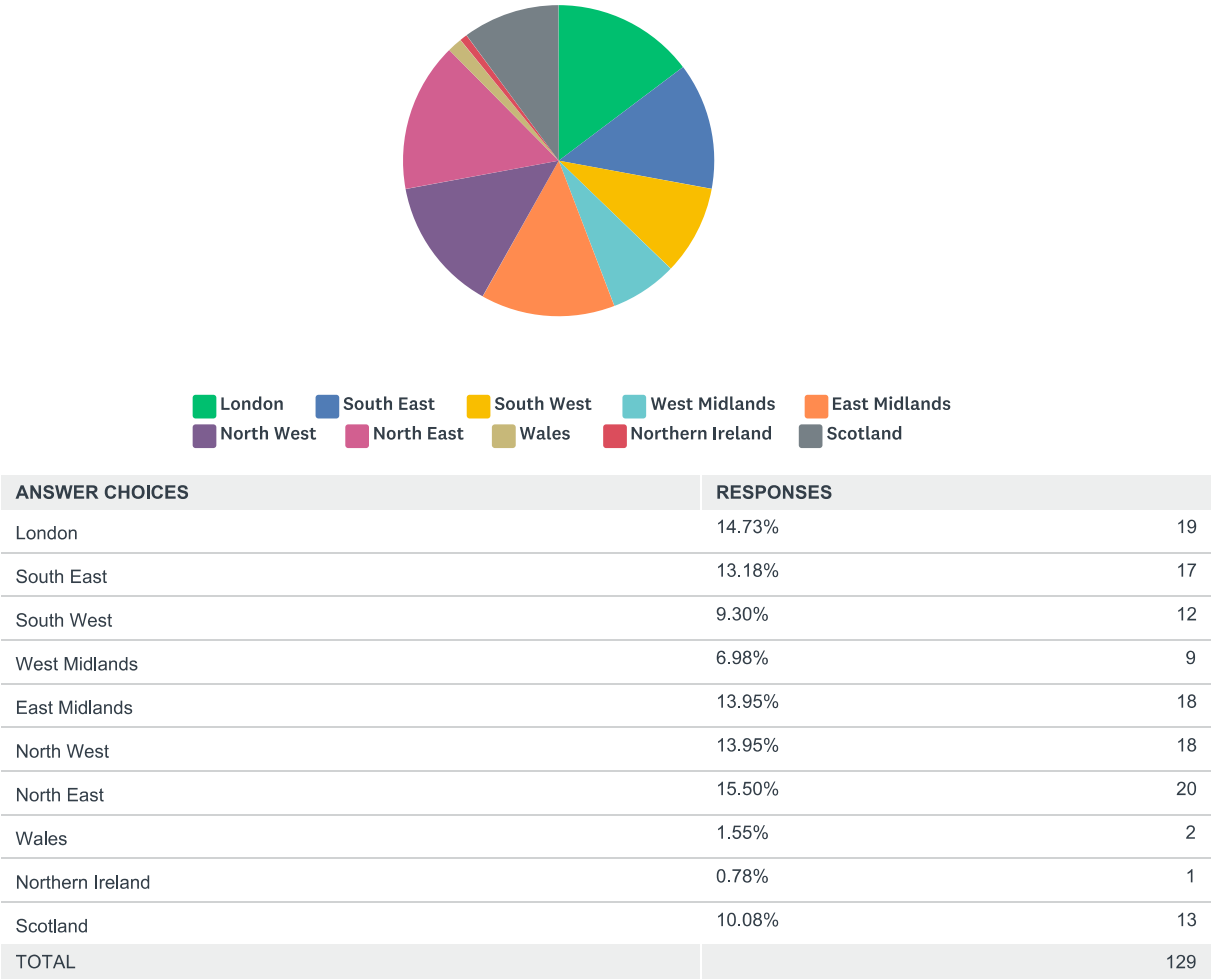


Figure 9: Distribution of responses to survey question 2: In what area of the UK is your organisation located?

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Question 3. What percentage of your trustee/director board do you consider identify as disabled people?

As discussed in the last chapter, one of the ODI criteria for an organisation to qualify as a DPULO was that at least 75% of its trustee/director board should identify as disabled people (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). Of the 12 DPULOs that took part in the stage 1 research, 11 claimed that they fulfilled this criterion, although it was noted that the ways in which CEOs interpreted ODI criteria varied. For example, one CEO stated that his/her organisation required that at least 51% of the trustee/director board should be family carers and disabled people. Therefore, this organisation would not qualify as a DPULO under this ODI criterion but might under other ODI criteria.

In question 3 of the survey, the CEOs were asked to select one of four ranges that they believed represented the percentage of their board members who identified as disabled people. A total of 128 of 133 CEOs responded to this question and their responses are shown in figure 10.

The survey returns indicated that a very significant majority (91 responses, just over 71%) claimed that at least 75% of their trustee/director board identified as disabled people. These organisations would therefore qualify as DPULOs under the relevant ODI criterion (ODI, 2011, cited in Bott, Sweeny and Watts, 2013).

However, a further criterion of the ODI for an organisation to qualify as a DPULO was that it should be led and controlled by disabled people (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). I believe that this specific criterion was unclear as it would indicate that any organisation with over 50% board members who identified as disabled people could also be considered a DPULO. Under this specific criterion an overwhelming majority of those who responded to question 3 of the survey (115 out of 128 responses, nearly 90%) could be considered to qualify as DPULOs (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). In contrast, taking these two criteria together would mean that 13 organisations would not qualify as DPULOs.

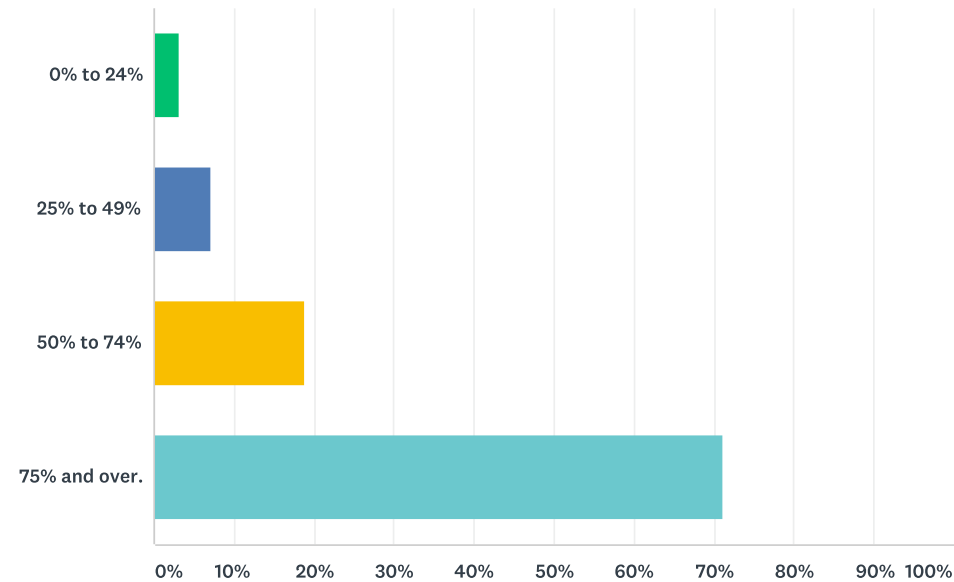
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As in the stage 1 research, the findings suggest that there appeared to be further confusion over the ODI requirement that an organisation should be led and controlled by disabled people to qualify as a DPULO (ODI, 2011, cited in Bott, Sweeny and Watts, 2013).

This is because it is unclear if this requirement referred to the trustee/director board and/or the membership. These findings echo the broader issues raised in chapter 6 about what it means to be a DPULO in the 2000s.

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Answered: 128 Skipped: 5



ANSWER CHOICES	RESPONSES
0% to 24%	3.13%4
25% to 49%	7.03%9
50% to 74%	18.75%24
75% and over.	71.09%91
TOTAL	128

Figure 10: *Distribution of responses to survey question 3: What percentage of your trustee/director board do you consider identify as disabled people?*

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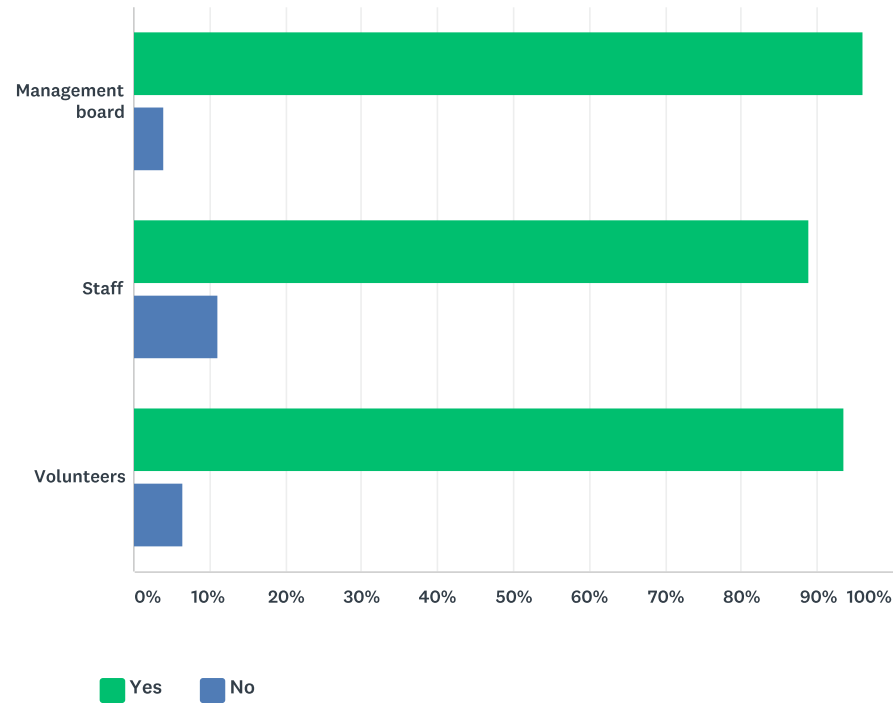
Question 4. Does your organisation have a commitment to recruit disabled people: on to your management board; as staff; and as volunteers?

An additional ODI criterion for an organisation to qualify as a DPULO was the ability to demonstrate a commitment to disabled people by employing disabled staff and volunteers (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). All 12 of the CEOs that took part in the stage 1 research stated that their DPULO employed disabled members of staff. Although CEOs were not specifically questioned about the employment of volunteers, three of the CEOs stated that their DPULO employed disabled volunteers. This ODI criterion can be viewed as unsatisfactory in that: it only specified a commitment, not a requirement, to the employment of disabled staff and volunteers; it appeared to suggest that it was necessary to employ both disabled staff and volunteers; and the term 'employing' was legally inappropriate when referring to volunteers. Consequently, it is unclear if the 12 organisations that took part in the stage 1 research fully qualified as DPULOs under this specific ODI criterion.

To better understand the applicability of this criterion, the CEOs were asked in survey question 4 to select the options that indicated if their organisation was committed or not to the recruitment of disabled people: on to their management board; as staff; and as volunteers. (Note: for the reasons given above, the term 'recruitment' was used in the wording of the question rather than the term 'employing'). A total of 129 CEOs provided responses to this question, however, as indicated in figure 11 not all of the CEOs responded to all options. However, the responses indicated that there was an overwhelming commitment by the organisations to recruit disabled people within all three categories. Thus, it is not unreasonable, in my view, that those organisations committed to the recruitment of disabled people in these categories could be considered as DPULOs. Yet again, this raises the problem of the potential flaws in the ODI's criterion and its interpretation by different CEOs as the definitions do not appear to fully capture the complexities of the changing role of DPULOs and the disability movement itself.

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Answered: 129 Skipped: 4



	YES	NO	TOTAL
Management board	96.09% 123	3.91% 5	128
Staff	88.89% 104	11.11% 13	117
Volunteers	93.55% 116	6.45% 8	124

Figure 11: *Distribution of responses to survey question 4: Does your organisation have a commitment to recruit disabled people: on to your trustee/director board; as staff; and as volunteers?*

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Question 5. Are you actively working towards recruiting disabled people to your organisation?

Turnbull (2012) noted that the ODI had expanded the definition of a DPULO to include those organisations that were actively working towards achieving its four qualifying criteria (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). Therefore, those organisations that did not previously satisfy the initial ODI criteria might qualify as DPULOs under this extended definition (ODI, 2011, cited in Bott, Sweeny and Watts, 2013).

However, to further explore the relevance of this expanded criteria to the wider population of DPULOs, question 5 asked the CEOs to indicate if they were actively working towards recruiting disabled staff and volunteers to their organisations. A total of 131 of 133 CEOs responded to this question and their responses are detailed in figure 12. The responses indicated that a significant majority (86 respondents or 65.6%) of the CEOs were actively working towards recruiting disabled staff and volunteers to their organisations.

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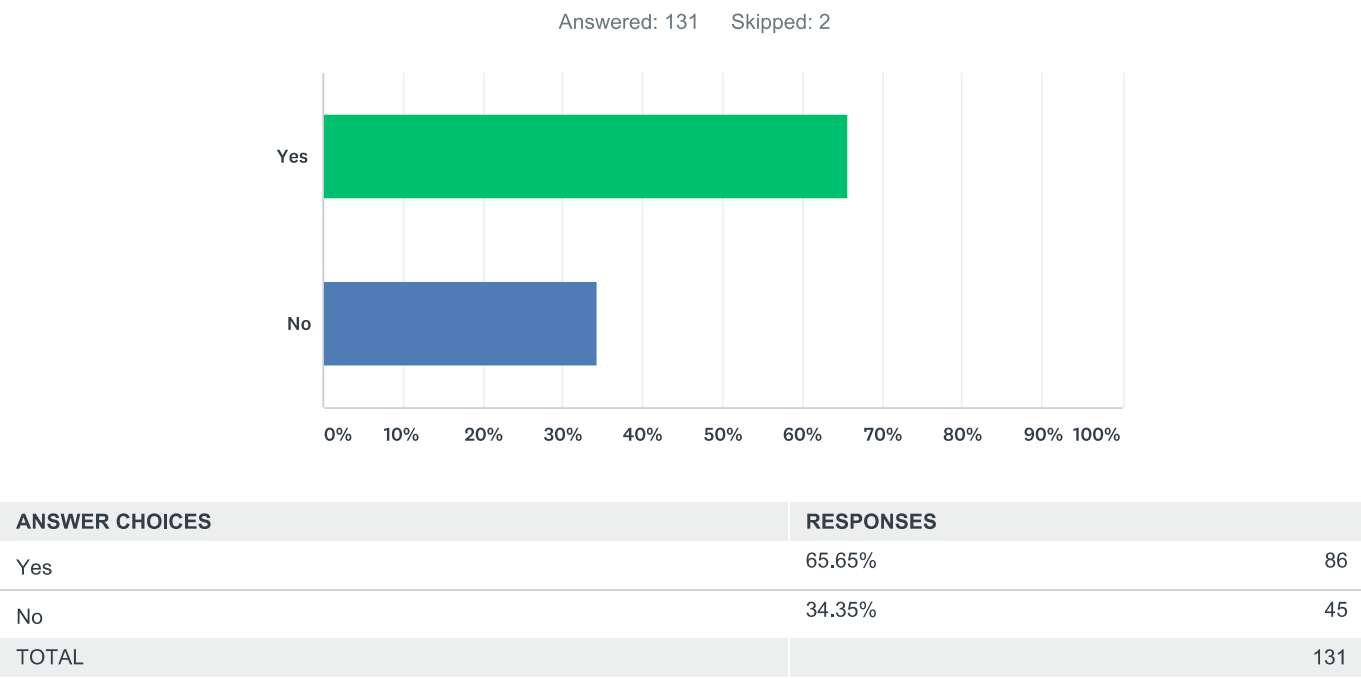


Figure 12: *Distribution of responses to survey question 5: Are you actively working towards recruiting disabled people to your organisation?*

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Question 6. Please could you name two key values, established by the UK disability movement, that you consider to be important to your organisation?

In the analysis of the interviews undertaken during the stage 1 research, it became apparent to me that all 12 of the CEOs recognised the importance of certain values that had been developed by the UK disability movement. Two key ethical values were identified during the analysis. Firstly, all 12 CEOs discussed the importance of independent living to their constituents (UPIAS, 1976) and secondly, 11 CEOs stated that their organisations followed the principles embraced in the social model of disability (Oliver, 1983, 1990a). Consequently, survey question 6 was formulated to identify those key values that were considered to be important in the wider population of DPULOs. Therefore, the CEOs were asked to identify two key values but were not required to prioritise their responses. Of the 133 CEOs that responded to the survey, 122 of the CEOs provided a response for value 1 and 120 provided a response for value 2, while 11 gave no answer.

As shown in table 5, the categories with most entries were: equality (71 entries or 29.8%); independent living (61 entries or 25.2%); and the social model of disability (58 entries or 24.0%). In contrast to these, the categories of User-Led (18), Representation (19) and Miscellaneous (15) each contained 19 entries or less. Thus, for purposes of this research, I have concluded that the first three categories were the most important to the CEOs.

While the concepts of independent living and the social model of disability were two of the three largest categories identified during the stage 2 survey analysis, the results did not appear to support to the same extent the importance placed on these concepts by the CEOs interviewed in stage 1 of the research. However, I have concluded that in the context of semi-structured interviews, these concepts would have been investigated in depth through the interaction between the interviewer and the interviewee. In contrast, this process of interaction would not have occurred when the CEOs involved in the stage 2 survey were responding to question 6. Consequently, I believed that this might have accounted for the differences between the results of the stage 1 and stage 2 research. In addition, being user-led might have been taken for granted by the CEOs given the focus of the study.

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During the stage 1 interviews, the concept of equality was not specifically addressed, however, the analysis of the transcripts identified Equality as a background thread during the discussions. Consequently, it is interesting that this value was accorded the highest score. Therefore, I have concluded that the perspective of Equality from the stage 1 research supported the results of the stage 2 survey. In contrast to the concept of Equality, the concept that disabled people's organisations should be user-led was frequently highlighted by the CEOs within the stage 1 semi-structured interviews. For example, 11 of the 12 CEOs indicated that at least 75% of their trustees/directors were disabled people. Therefore, their organisations were considered to be user-led. In addition, eight of the 12 organisations were regarded as being user-led by the virtue of offering a full-membership category that only included disabled people. However, the responses to survey question 6 did not appreciably support the concept of being user-led that was identified in the stage 1 research. In contrast to these concepts, the concept of representation did not appear to be a key value in either the stage 1 or stage 2 research.

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Value	Count
Independent living / Choice and control	61
User-led	18
Equality	71
Representation	19
Social model	58
Miscellaneous	15
TOTAL	242

Table 5: *Distribution of responses to survey question 6: Please could you name two key values, established by the UK disability movement, that you consider to be important to your organisation?*

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7.5.2 Income

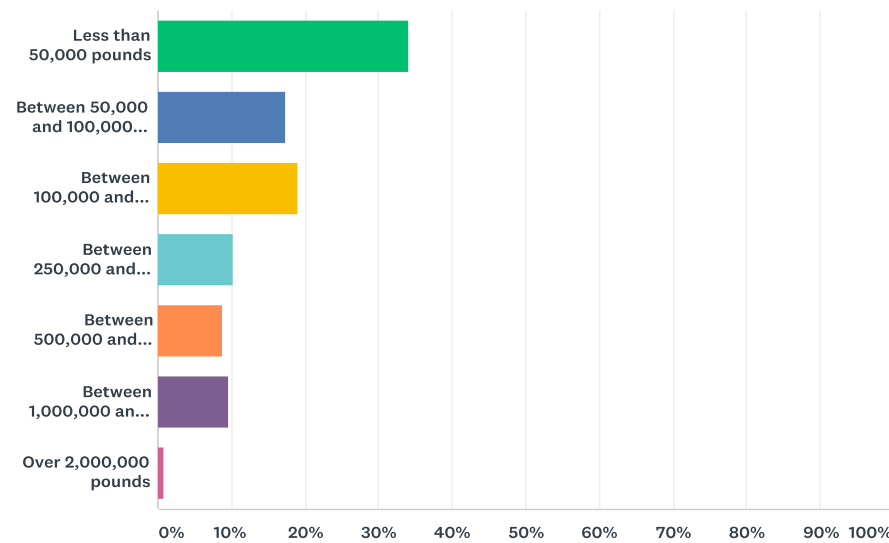
Question 7. Please could you provide details of your organisation's total income, from all sources, for the financial year 2011/12?

In literature review 2 (chapter 3), an analysis of the finances of four DPULOs located outside of the London area was undertaken in order to compare their variations in income with that of the Deaf and Disabled People's Organisations (DDPOs) detailed in the Inclusion London (2012) report. The analysis revealed that through the years 2007 to 2012 inclusive, the income of these four DPULOs varied but was between £300,000 and £1,650,000 per annum during this period. Therefore, this range of incomes would have placed the four DPULOs within the medium or large categories of voluntary organisations as defined by the National Council for Voluntary Organisations (NCVO) (2016). Also, the income of my own DPULO over the same period was such that it would have been placed in the large category of voluntary organisations (NCVO, 2016). The intention of survey question 7 was to investigate the annual incomes of the full population of DPULOs. A total of 126 of 133 CEOs responded to this question and their responses are detailed in figure 13.

The responses indicated that 65 (51.5%) of the organisations had incomes of less than £100,000 per annum and could therefore be considered as micro or small voluntary organisations as defined by the NCVO (2016). In contrast, only 13 (10.3%) of the organisations had annual incomes of more than £1,000,000 and could therefore be considered as large or major voluntary organisations (NCVO, 2014). In part of the analysis undertaken by the NCVO (2014), the categories of micro and small voluntary organisations were combined and it was claimed that they 'are less likely to employ paid staff and rely more on donations from individuals rather than larger organisations' (NCVO, 2014, p.2). Earlier findings indicated that the growth of DPULOs appeared to have had a steady increase since the 1980s. However, this finding suggested that more than half of the organisations are likely to be micro and therefore particularly vulnerable to austerity policies.

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Answered: 126 Skipped: 7



ANSWER CHOICES	RESPONSES	
Less than 50,000 pounds	34.13%	43
Between 50,000 and 100,000 pounds	17.46%	22
Between 100,000 and 250,000 pounds	19.05%	24
Between 250,000 and 500,000 pounds	10.32%	13
Between 500,000 and 1,000,000 pounds	8.73%	11
Between 1,000,000 and 2,000,000 pounds	9.52%	12
Over 2,000,000 pounds	0.79%	1
TOTAL		126

Figure 13: *Distribution of responses to survey question 7: Please could you provide details of your organisation's total income, from all sources, for the financial year 2011/12?*

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Question 8. Since 2010, has your organisation received income from the following sources and, if the answer is 'yes', how has that income changed²?

As discussed in literature review 2 (chapter 3), the Inclusion London (2012, p.5) report appeared to differentiate between the terms 'funding' and 'income', where funding referred to revenue from local and national government sources while income referred to all revenue sources. The Inclusion London (2012, p.5) report stated that of 54 DDPOs surveyed, some 40 (74.1%) had experienced cuts in funding: of these, 24 experienced 'cuts in total income' of up to 20% while the remainder experienced cuts of between 20% and 100%. 31 DDPOs expected further cuts in funding in 2012/13, while 23 predicted that they might experience a reduction in total income, but at the time the survey was undertaken they lacked sufficient information to reach such a firm conclusion (Inclusion London, 2012). However, the report findings stressed that 'the biggest reductions in funding' to DDPOs 'came from Local Authority funding sources' (Inclusion London, 2012, p.5).

The financial analysis of the four DPULOs from outside of the London area, also detailed in literature review 2 (chapter 3), indicated that three of the four (75%) had experienced similar reductions in total income to those mentioned in the Inclusion London (2012) report. In the stage 1 research, 8 out of 12 CEOs indicated that their organisation had experienced funding cuts, where national and local government sources were specifically mentioned. Similarly, from my personal experience as the chairman of a DPULO, I can confirm that my own organisation suffered comparable financial cuts.

The Inclusion London (2012) report, the analysis of the four DPULOs from outside of the London area and the stage 1 research investigated in detail the specific revenue sources of the organisations involved. Consequently, in survey question 8, the CEOs were asked to indicate, firstly, if their organisation received income from a list of specified sources and secondly, where appropriate, if that income had changed. The intention of this question was to investigate the sources of income and, where appropriate, if these had changed within the wider population of DPULOs. Depending on the stated income source, between 105 and 117 of the 133 CEOs responded. The responses are detailed in figure 14.

² Note: refer to figure 14 for the specific sources

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The analysis by income source is detailed as follows:

Local and national government contracts

117 CEOs responded to this option. Of these, 52 (44.4%) indicated that their organisation received no income from these sources. Of the other 65 responses, 31 (26.5%) had seen a decrease in their income from these sources while 20 (17.1%) had seen an increase.

Local and national government grants

115 CEOs responded to this option. Of these, 29 (25.2%) indicated that their organisation received no income from these sources. Of the other 86 responses, 24 (20.9%) had seen a decrease in their income from these sources while 40 (34.8%) had seen an increase.

Grants from foundations and other grant making organisations

115 CEOs responded to this option. Of these, 14 (12.2%) indicated that their organisation received no income from these sources. Of the other 101 responses, 28 (24.4%) had seen a decrease in their income from these sources while 47 (40.9%) had seen an increase.

Income from investments and legacies

105 CEOs responded to this option. Of these, 83 (79.1%) indicated that their organisation received no income from these sources. Of the other 22 responses, five (4.8%) had seen a decrease in their income from these sources while six (5.7%) had seen an increase.

Income from commercial enterprise

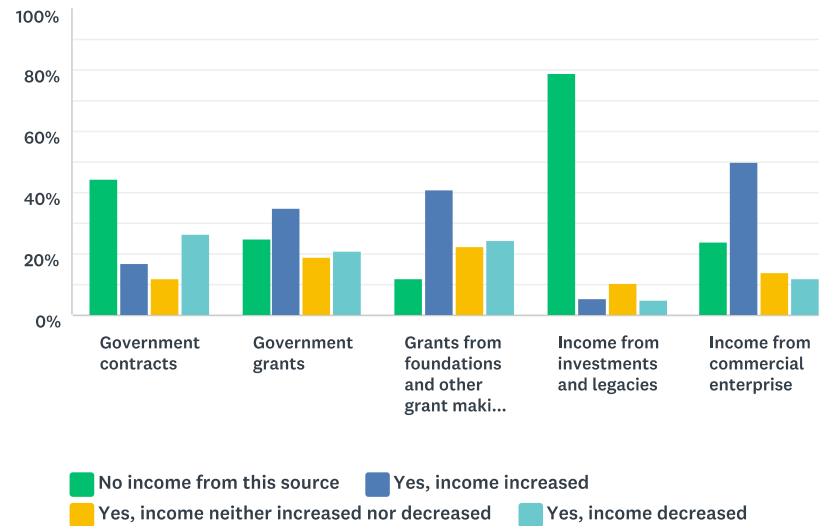
116 CEOs responded to this option. Of these, 28 (24.1%) indicated that their organisation received no income from these sources. Of the other 88 responses, 14 (12.1%) had seen a decrease in their income from these sources while 58 (50.0%) had seen an increase.

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In general terms, the survey results indicated that there was a reduction in funding to DPULOs from local and national government contracts. However, these reductions were less dramatic than those identified in the Inclusion London (2012) report, the analysis of the four DPULOs and the stage 1 research. There was also an increase in funding to DPULOs from local and national government grants, although these increases contradicted the conclusions reached in the Inclusion London (2012) report. In addition, there was an increase in grants from foundations and other grant-making organisations. These increases also contradicted the conclusions reached in the Inclusion London (2012) report. A significant majority of DPULOs did not receive any revenue from investments and legacies. No suitable comparisons could be made as this revenue source was not investigated in the earlier stages the research. There was a significant increase in revenue from commercial activities. Similarly, no suitable comparisons could be made as this revenue source was not investigated in the earlier stages of this thesis. However, the percentage of DPULOs that undertook commercial activities was greater in the survey than that identified through the stage 1 research.

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Answered: 125 Skipped: 8



	NO INCOME FROM THIS SOURCE	YES, INCOME INCREASED	YES, INCOME NEITHER INCREASED NOR DECREASED	YES, INCOME DECREASED	TOTAL
Government contracts	44.44% 52	17.09% 20	11.97% 14	26.50% 31	117
Government grants	25.22% 29	34.78% 40	19.13% 22	20.87% 24	115
Grants from foundations and other grant making organisations	12.17% 14	40.87% 47	22.61% 26	24.35% 28	115
Income from investments and legacies	79.05% 83	5.71% 6	10.48% 11	4.76% 5	105
Income from commercial enterprise	24.14% 28	50.00% 58	13.79% 16	12.07% 14	116

Figure 14: Distribution of responses to survey question 8: Since 2010, has your organisation received income from the following sources and, if the answer is 'yes', how has that income changed?

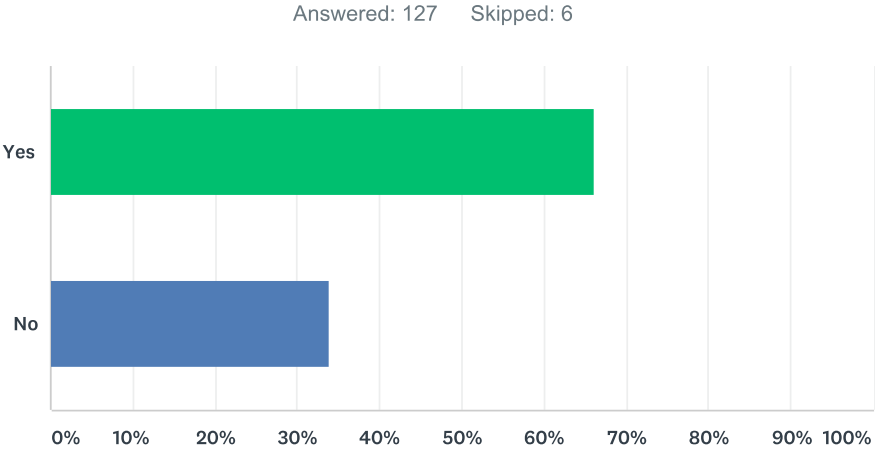
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Question 9. Since 2010, have you found it necessary to use your financial reserves to support your organisation's activities?

In the stage 1 research, eight of the 12 CEOs stated that their organisation had experienced a range of financial challenges. Of these, one alluded to the use of their financial reserves as a cushion to offset a reduction in total income. Similarly, my own analysis of four DPULOs detailed in literature review 2 (chapter 3) concluded that three (75%) had utilised their financial reserves to support service provision (Charity Commission, 2012). Therefore, I felt it was important in analysing the results of question 9 to compare the incidence in the use of financial reserves between the stage 1 research, my own analysis of the four DPULOs in literature review 2 (chapter 3) and the full population of DPULOs. A total of 127 of 133 CEOs responded to this question and their responses are shown in figure 15.

The responses indicated that 84 respondents (66.1%) of the organisations involved in the stage 2 survey had found it necessary to use their financial reserves to support their organisations' activities. The results showed that a slightly smaller majority of the organisations had found it necessary to utilise their reserves than was reflected in my analysis of the four DPULOs as outlined in literature review 2 (chapter 3) (approximately 66% as opposed to 75%). Therefore, the results from the stage 2 survey suggested that a majority of DPULOs might be in danger of closure if they continued to use their financial reserves to support their organisations activities (Gaskill et al., 1993). However, this result was not reflected in the stage 1 research where only one CEO had used his/her organisation's financial reserves to offset reductions in total income.

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ANSWER CHOICES	RESPONSES	
Yes	66.14%	84
No	33.86%	43
TOTAL		127

Figure 15: *Distribution of responses to survey question 9: Since 2010, have you found it necessary to use your financial reserves to support your organisation’s activities?*

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7.5.3 Key challenges for the DPULOS

Question 10. Please indicate the level of concern for your organisation's future ability to provide services, with reference to the following issues.³

In the analysis of the interviews undertaken during the stage 1 research, the CEOs identified a range of issues that they believed had affected their organisations' ability to provide services. These issues included: competition from businesses and other charities; staff and volunteer recruitment/turnover; changes to local and national government commissioning processes; and the viability of their organisations. In the course of literature review 2 (chapter 3), Inclusion London (2012) and Williams (2014) detailed a similar range of issues. In addition, my own organisation experienced such an impact through issues such as time writing bids and strategic planning processes. The intention of survey question 10 was to investigate the impact of such issues on the future ability of the wider population of DPULOs to provide services. Between 115 and 121 of the 133 CEOs responded depending on the issue presented in question 10 and their responses are detailed in figure 16. The analysis by issue is detailed as follows:

Time writing bids

119 CEOs responded to this option. Of these, 112 (94.1%) indicated that time writing bids was of some concern to their organisations future ability to provide services. However, 77 CEOs (64.7%) indicated that time writing bids was of a high level of concern.

Strategic planning processes

117 CEOs responded to this option. Of these, 109 (93.2%) indicated that strategic planning processes were of some concern to their organisations' future ability to provide services with 71 CEOs (60.7%) indicating that strategic planning processes were of a high level of concern.

³ Note: refer to figure 16 for the specific issues

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Staff and volunteer recruitment/retention

115 CEOs responded to this option. Of these, 62 (66.9%) indicated that Staff and volunteer recruitment/retention was of some concern to their organisations future ability to provide services. However, only 17 CEOs (14.8%) indicated that staff and volunteer recruitment/retention was of a high level of concern.

The viability of their organisation

119 CEOs responded to this option. Of these, 109 (91.6%) indicated that the viability of their organisation was of some concern to their organisations future ability to provide services with 54 CEOs (45.4%) indicated that the viability of their organisation was of a high level of concern.

Competition from businesses and other charities

121 CEOs responded to this option. Of these, 105 (86.8%) indicated that competition from businesses and other charities was of some concern to their organisations future ability to provide services. However, 56 CEOs (46.3%) indicated that competition from businesses and other charities was of a high level of concern.

Changes to local and national government commissioning processes

120 CEOs responded to this option. Of these, 104 (86.7%) indicated that changes to local and national government commissioning processes was of some concern to their organisations' future ability to provide services. However, 66 CEOs (55.0%) indicated that changes to local and national government commissioning processes was of a high level of concern.

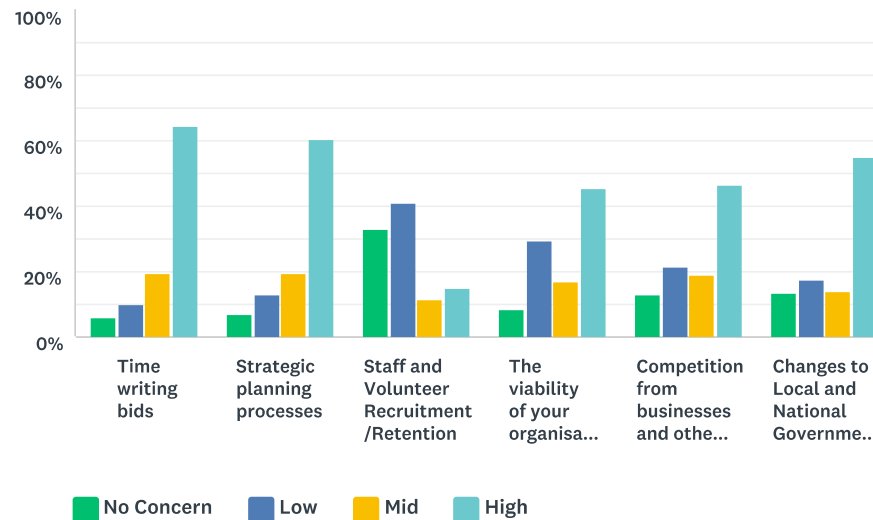
In general terms, survey question 10 indicated that the CEOs believed that all of the issues were either of some concern or a high level of concern to their organisations' future ability to provide services. Time to write bids and strategic planning coming out as having the highest levels of concern. This view was supported by the stage 1 research, Inclusion London (2012), Williams (2014) and my personal experience as the chairman of a DPULO.

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However, the CEOs also indicated that they were less concerned about the impact of staff and volunteer recruitment/retention on their organisations' future ability to provide services.

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Answered: 121 Skipped: 12



	NO CONCERN	LOW	MID	HIGH	TOTAL
Time writing bids	5.88% 7	10.08% 12	19.33% 23	64.71% 77	119
Strategic planning processes	6.84% 8	12.82% 15	19.66% 23	60.68% 71	117
Staff and Volunteer Recruitment/Retention	33.04% 38	40.87% 47	11.30% 13	14.78% 17	115
The viability of your organisation	8.40% 10	29.41% 35	16.81% 20	45.38% 54	119
Competition from businesses and other charities	13.22% 16	21.49% 26	19.01% 23	46.28% 56	121
Changes to Local and National Government commissioning processes	13.33% 16	17.50% 21	14.17% 17	55.00% 66	120

Figure 16: *Distribution of responses to survey question 10: Please indicate the level of concern for your organisation's future ability to provide services, with reference to the following issues*

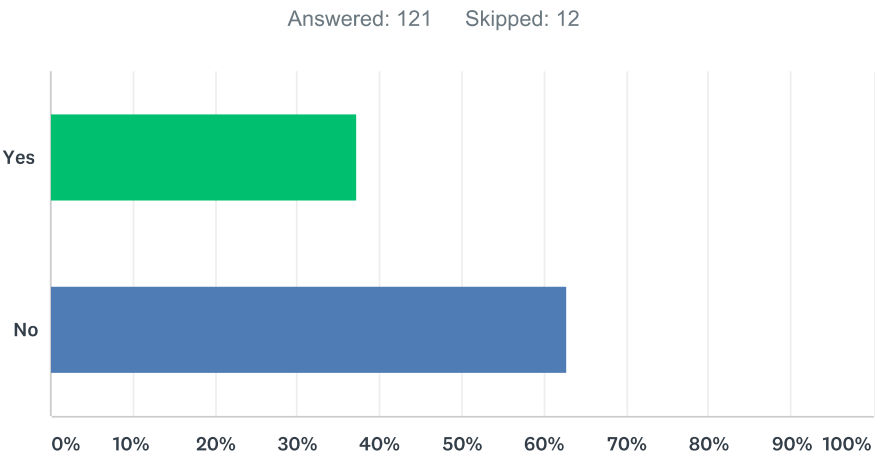
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Question 11. Does your organisation experience problems with recruiting disabled people to serve on your management board?

In the stage 1 research, six of the 12 CEOs stated that their organisation experienced problems with recruiting disabled people to serve on their management boards. As the chairman of a DPULO, I have experienced similar problems by being unable to fill vacancies for disabled people to serve on my management board. Therefore, the aim of question 11 was to compare the experiences of the six CEOs from the stage 1 research with the full population of DPULOs. A total of 121 of 133 CEOs responded to this question and their responses are detailed in figure 17.

The responses indicated that 45 respondents or 37.2% of the organisations had experienced problems with recruiting disabled people to serve on their management boards. This result showed that a smaller percentage of the organisations experienced problems recruiting disabled people to serve on their management boards than was reflected in the analysis of the stage 1 research (approximately 37% as opposed to 50%).

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ANSWER CHOICES	RESPONSES	
Yes	37.19%	45
No	62.81%	76
TOTAL		121

Figure 17: *Distribution of responses to survey question 11: Does your organisation experience problems with recruiting disabled people to serve on your management board?*

CHAPTER 7

Question 12. What skills are lacking in your organisation?

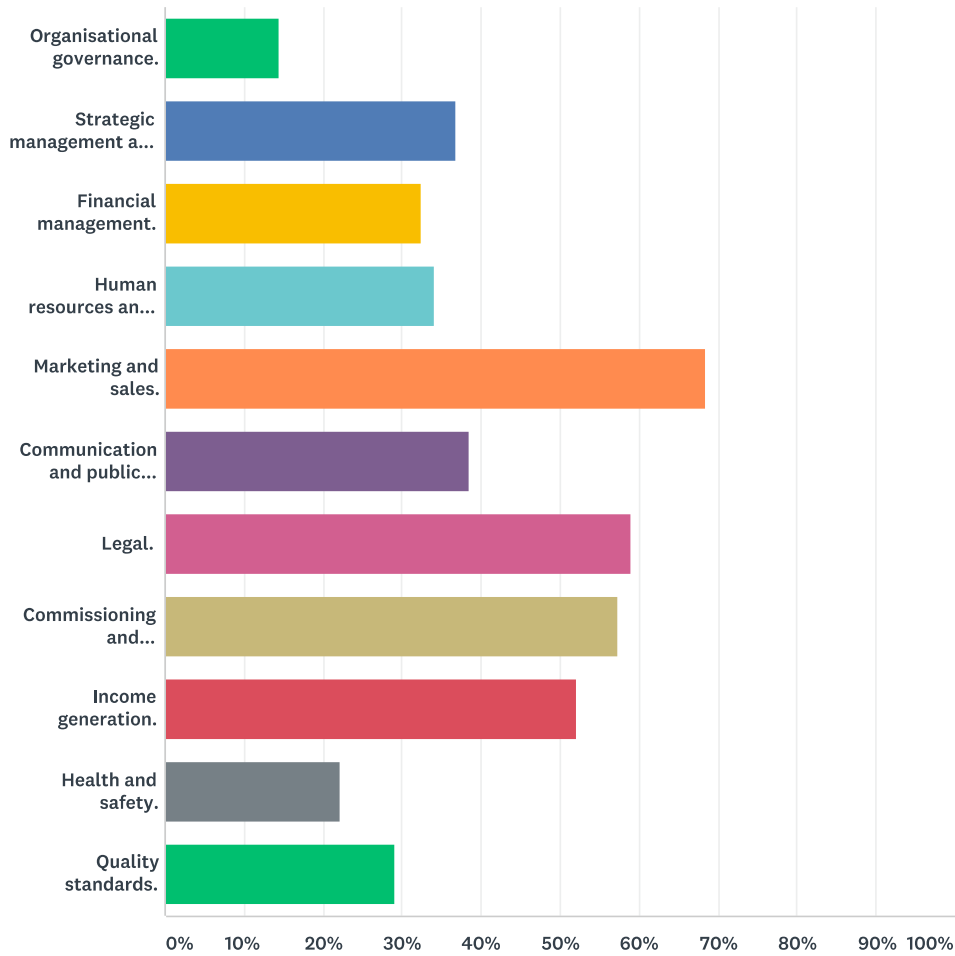
In the stage 1 research, six of the 12 CEOs described a range of skills that they felt were lacking in their organisations. These included: marketing; HR support; governance; IT support; and accountancy. As the chairman of a DPULO, I was aware that my own organisation lacked skills such as: quality management; income generation; and legal representation. Therefore, the intention of question 12 was to identify the skills that were lacking in the full population of DPULOs. A total of 117 of 133 CEOs responded to this question and their responses are detailed in figure 18.

The responses indicated that: marketing and sales (68.4%); legal (59.0%); commissioning and procurement (57.3%); and income generation (52.1%) were the skills that were shown to be lacking in more than 50% of the organisations.

These findings demonstrated that in general, DPULOs lacked the professional and business skills necessary to compete effectively with other organisations in local authority contract commissioning processes.

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Answered: 117 Skipped: 16



ANSWER CHOICES	RESPONSES	
Organisational governance.	14.53%	17
Strategic management and business development.	36.75%	43
Financial management.	32.48%	38
Human resources and workforce management.	34.19%	40
Marketing and sales.	68.38%	80
Communication and public relations.	38.46%	45
Legal.	58.97%	69
Commissioning and procurement.	57.26%	67
Income generation.	52.14%	61
Health and safety.	22.22%	26
Quality standards.	29.06%	34
Total Respondents: 117		

Figure 18: *Distribution of responses to survey question 12: What skills are lacking in your organisation?*

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Question 13. Does your organisation offer an appraisal scheme to: your management board; your staff; and your volunteers?

In the stage 1 research, five of the 12 CEOs stated that their organisations offered a staff appraisal scheme. One of the CEOs stated that their organisation offered such a scheme to their management board, while none of the CEOs specifically stated that their organisation offered appraisals to their volunteers. However, the NCVO (2018) claimed that those voluntary sector organisations that could plan and undertake an effective supervision and appraisal process were better able to support the needs of their clients.

One of the key areas of responsibility for me as the chairman of a DPULO was to present feedback to my board of trustees and the members of my senior management team about their performance and to identify training and development needs. The members of my management team were required to undertake a similar process with their subordinates. The process that was available to both myself and my team to undertake this activity was through an appraisal scheme that was applicable to all members of the workforce. I therefore considered it important to investigate the apparent differences in the use of appraisal schemes between the stage 1 findings, the recommendations of the NCVO (2018), my own personal experience and within the DPULOs involved in this research.

Therefore, to better understand the importance given to appraisal schemes by the wider population of DPULOs, the CEOs were asked in survey question 13 to select the options that indicated if their organisations offered an appraisal scheme to: their management board; their staff; and their volunteers. In total, 119 of 133 CEOs selected at least one option in answer to the question. Of these, 117 CEOs selected the management board option, 117 selected the staff option and 116 selected the volunteer option.

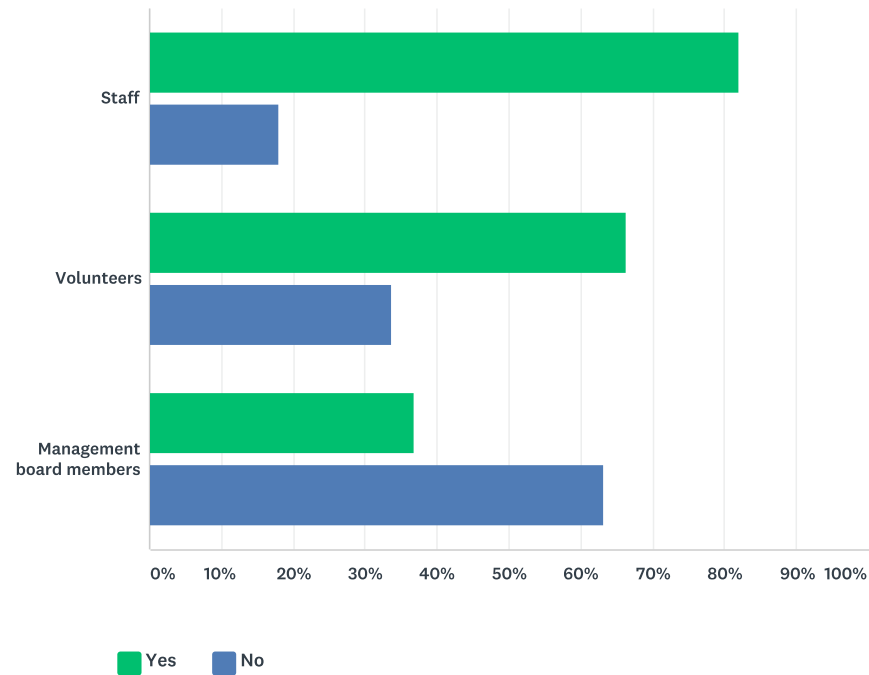
The responses to survey question 13 are detailed in figure 19. The responses indicated that approximately 82% of the organisations undertook appraisals with their staff, 66% with their volunteers but only 37% with their management board members. The results showed that a majority of the organisations offered an appraisal scheme that applied to both their staff and volunteers. In contrast, only a minority of the CEOs stated that their organisation offered appraisals to their board members.

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Thus, the organisations who did not offer an appraisal scheme to their management boards were failing to follow recognised governance processes and might not be fulfilling their overall organisational responsibilities (WCVA, 2013).

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Answered: 119 Skipped: 14



	YES	NO	TOTAL
Staff	82.05% 96	17.95% 21	117
Volunteers	66.38% 77	33.62% 39	116
Management board members	36.75% 43	63.25% 74	117

Figure 19: *Distribution of responses to survey question 13: Does your organisation offer an appraisal scheme to: your management board; your staff; and your volunteers?*

CHAPTER 7

Question 14. Do you offer training and development opportunities to all members of your workforce?

In the stage 1 research, 10 of the 12 CEOs indicated that their organisation offered training and development opportunities to their workforce. This was reflected in my own DPULO where, as chairman, I was responsible for identifying appropriate training and development opportunities for my board of trustees and senior management team. This ongoing process was formally reviewed during the annual appraisals (NCVO, 2018). The members of my management team were required to undertake a similar process with their subordinates. Therefore, question 14 was formulated to confirm if the stage 1 results were reflected in the wider population of DPULOs. The CEOs were asked to indicate if their organisations offered training and development opportunities to all members of their workforce.

A total of 117 of 133 CEOs responded to this question and their responses are shown in figure 20. The responses indicated that a significant majority (75.2%) of the organisations offered training and development opportunities to all members of their workforce and consequently fulfilled the recommendations of the NCVO (2018). However, approximately a quarter of the organisations did not offer such opportunities and, therefore, their management boards were failing to follow the recognised governance processes in the area of training and development as detailed by the Welsh Council for Voluntary Action (WCVA) (2013).

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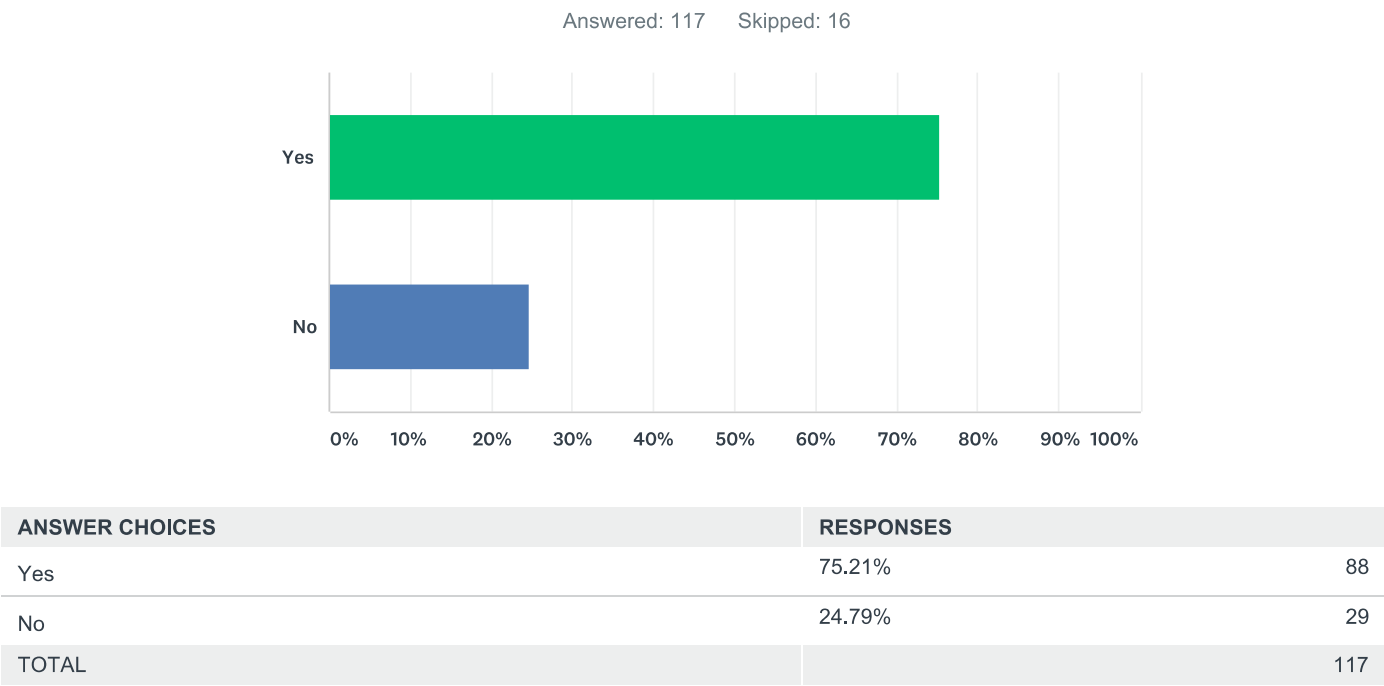


Figure 20: *Distribution of results for survey question 14: Do you offer training and development opportunities to all members of your workforce?*

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Question 15. Does your organisation operate a recognised quality management system (QMS) (for instance: ISO 9001, PQASSO, Investors in People or similar)?

In the stage 1 research, seven of the 12 CEOs stated that their organisation operated a QMS, including, for example: ISO9001 (BSI, 2018); PQUASSO (NCVO, 2017); Investors in People (Investors in People, 2018). My own organisation did not operate a formal quality system, however, I believe that suitable methods had been put in place to ensure that high quality services were provided to our clients, including, for instance, the use of an informal feedback system.

As the stage 1 results indicated that just over half of the organisations operated a recognised QMS, the intention of question 15 was to gain a better understanding of the use of such systems within the wider population of DPULOs. Therefore, the CEOs were asked to indicate if their organisation operated a recognised QMS.

A total of 119 of 133 CEOs responded to this question and their responses are detailed in figure 21. The responses indicated that under half (49 responses or approximately 41%) of the organisations operated a recognised QMS. The Improving the Life Chances of Disabled People policy document (PMSU, 2005) stated that user-led organisations should develop high quality services to support their clients. The NVCO (2017) recommended that a suitable method for such organisations to ensure that they offered high quality services was through the application of the practices inherent in a recognised QMS. The results from the survey demonstrated that a majority of the organisations did not operate a recognised QMS and therefore did not adhere to the NVCO (2017) recommendations.

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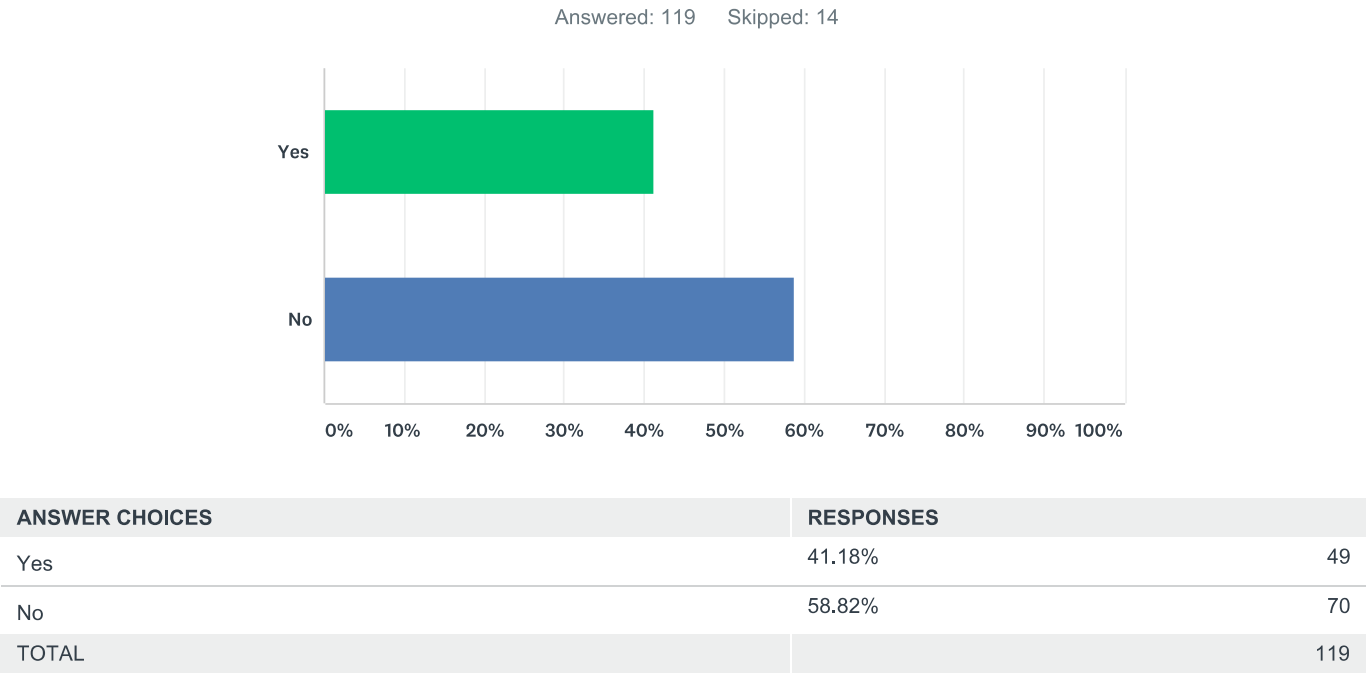


Figure 21: *Distribution of results for survey question 15: Does your organisation operate a recognised Quality Management System (QMS) (for instance: ISO 9001, PQASSO, Investors in People or similar)?*

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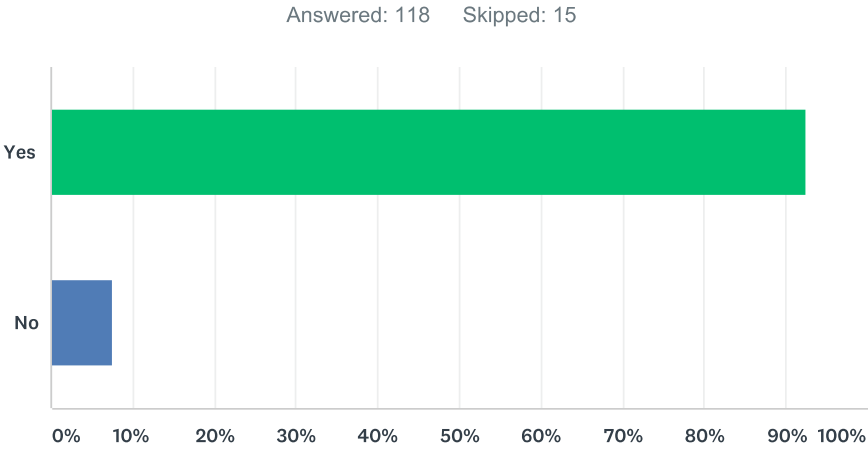
Question 16. Do you seek feedback from your clients to monitor the quality of the services offered by your organisation?

During the discussion covering the topic of quality standards, three of 12 CEOs in the stage 1 research stated that their organisation used feedback mechanisms, such as questionnaires, for monitoring the quality of the services provided to their clients. My own organisation utilised mechanisms that included surveys, focus groups and interviews with individuals, in order to monitor, maintain and improve the quality of our services. In view of my personal experience, I felt that it was unclear whether the responses of just three CEOs was indeed fully representative of the full population of DPULOs.

Therefore, question 16 asked the CEOs to indicate if they sought feedback from their clients in order to monitor the quality of services offered by their organisation. A total of 118 of 133 CEOs responded to this question and their responses are detailed in figure 22.

The responses indicated that an overwhelming majority (109 responses or 92.4%) of the organisations sought feedback from their clients in order to monitor the quality of the services they offered. These figures demonstrated that a much higher percentage of organisations utilised feedback mechanisms than those that claimed they followed a QMS.

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ANSWER CHOICES	RESPONSES	
Yes	92.37%	109
No	7.63%	9
TOTAL		118

Figure 22: *Distribution of results for survey question 16: Do you seek feedback from your clients to monitor the quality of the services offered by your organisation?*

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Question 17. Does your organisation operate a complaints procedure?

During the stage 1 interviews, while discussing quality standards, only one of the 12 CEOs specifically mentioned that his/her organisation operated a complaints procedure. The CEO indicated that this complaints procedure was used as a supplementary method of obtaining feedback from clients about the quality of the services offered by his/her organisation. In my own organisation a complaints procedure was considered to be an essential method for obtaining feedback about the quality of the services offered. However, although only one of the CEOs involved in the stage 1 research discussed the use of a complaints procedure, I felt that this subject should be further investigated within the full population of DPULOs.

Therefore, in question 17, the CEOs were asked to indicate if their organisation operated a formal complaints procedure. A total of 117 of 133 CEOs responded to this question and their responses are shown in figure 23. The responses indicated that an overwhelming majority (94%) of the organisations operated a complaints procedure.

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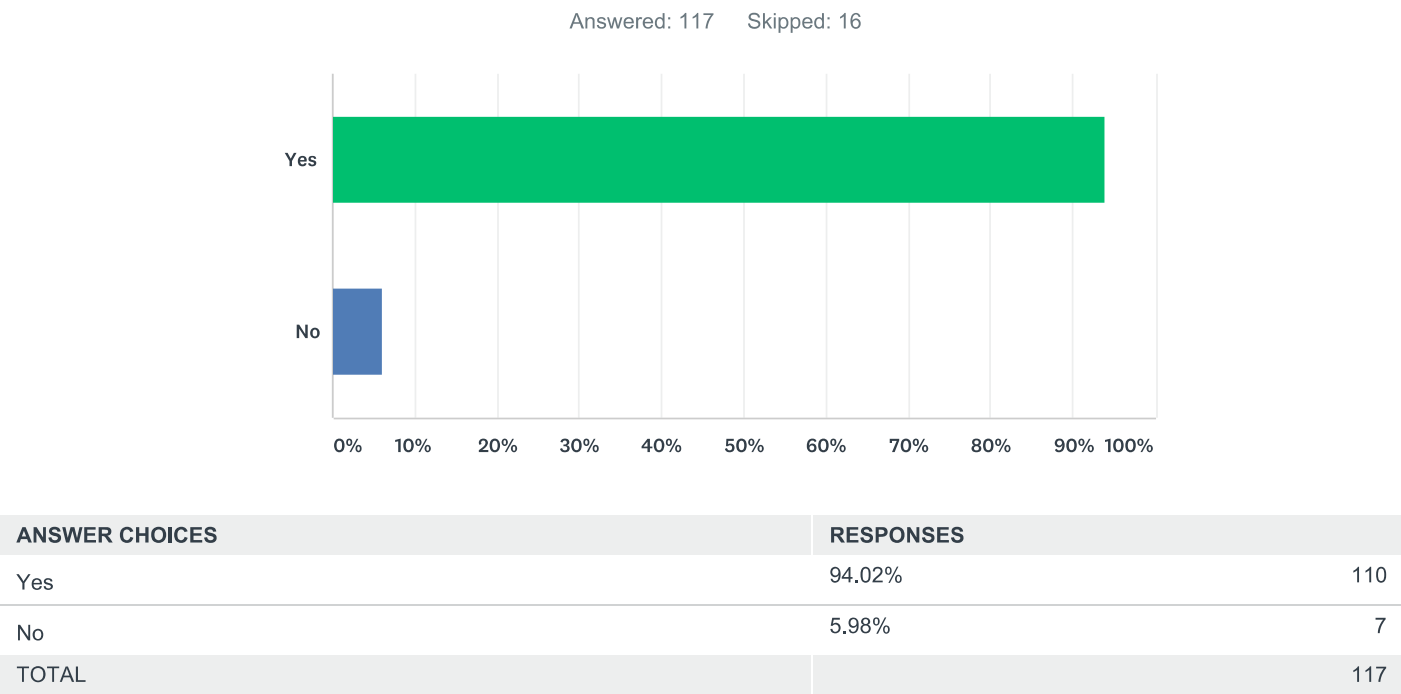


Figure 23 *Distribution of results for survey question 17: Does your organisation operate a complaints procedure?*

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Question 18. How many commercial enterprises have purchased a service or services from you over the last 12 months?

During the stage 1 interviews, five of the 12 CEOs indicated that their organisation had introduced commercial services to augment other sources of income. Consequently, question 18 was formulated in order to identify the incidence of commercial activity that had occurred within the full population of DPULOs. Therefore, the intention of this question was to ask the CEOs to indicate the number of commercial enterprises that had purchased a service or services from their organisation over the last 12 months. A total of 100 of 133 CEOs responded to this question.

As shown in table 6, the highest number of responses was for that of zero commercial enterprises (46 responses or 46%), followed by those of one and two commercial enterprises with 12 responses (12%) each. The number of responses for each of three, four and five commercial enterprises totalled seven or less. There were 13 responses for the range 6 to 100 commercial enterprises. A detailed breakdown of this range is provided in table 7.

In answering question 18, just over half of the CEOs who responded indicated that one or more commercial enterprises had purchased a service or services from their organisation during the previous 12 months. Therefore, just under half of the CEOs indicated that their organisation had not sold any services to commercial enterprises during the same year. In addition, a total of 41 CEOs indicated that their organisation had sold services to one to five commercial enterprises (inclusive) during that year. Consequently, a significant number of the CEOs (87% of the responses) indicated that their organisation sold services to five or fewer commercial enterprises during the year. In contrast, two of the CEOs claimed that their organisation had sold services to 50 or more commercial enterprises over the same period.

The responses to question 18 appeared to show that a larger percentage of DPULOs sold services to commercial enterprises than was reflected in the analysis of the stage 1 interviews (54% as opposed to approximately 42%).

This suggested that the majority of DPULOs that had sold services to commercial enterprises over the last 12 months were only superficially involved in commercial activities.

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Nevertheless, the increased frequency in which these organisations were selling their services indicated that there was a realisation amongst CEOs that they should introduce income streams to replace those lost from local authority contracts. In addition, two of the CEOs appeared to have fully developed commercial activities to augment their organisations' income. However, it was not known if these DPULO's development of commercial activities was influenced by losses from local authority contracts.

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Answer Choices	Responses
0	46.00% 46
1	12.00% 12
2	12.00% 12
3	7.00% 7
4	4.00% 4
5	6.00% 6
6-100	13.00% 13
TOTAL	100

Table 6: *Distribution of results for survey question 18.
How many commercial enterprises have purchased a service or services from you over the last 12 months?*

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Answer Choices	Responses
6	1
8	3
10	1
12	1
20	2
24	1
30	1
32	1
50	1
100	1
TOTAL	13

Table 7: Breakdown of 6-100 range for responses to survey question 18.

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Question 19. Has your organisation experienced competition with other DPULOs?

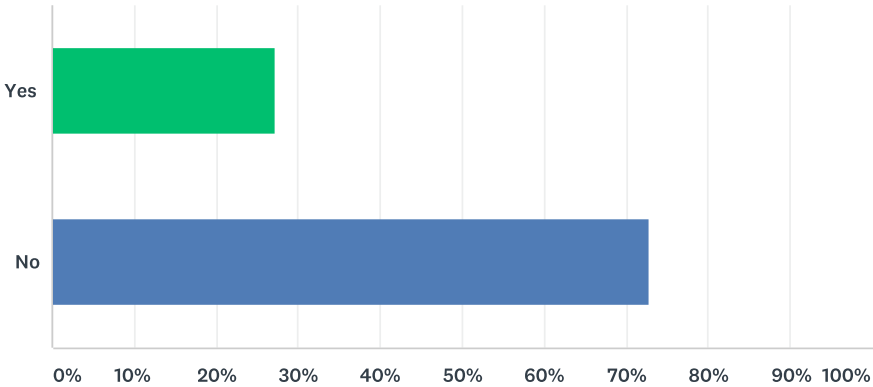
During literature review 2 (chapter 3), the Inclusion London (2012) report and Williams (2014) highlighted the issue of competition with businesses and national charities.

In the stage 1 research, seven of the 12 CEOs indicated that they had experienced such competition with national organisations while three had with other DPULOs. Similarly, my own organisation had experience of such competition with other DPULOs. Therefore, the intention of question 19 was to determine if the wider population of DPULOs had experienced competition with other such organisations. A total of 114 of 133 CEOs responded to this question and their responses are detailed in figure 24.

The responses indicated that only 31 (27.2%) of the DPULOs had experienced competition with other such organisations. This rate of response is similar to that of the stage 1 research (approximately 27% as opposed to 25%).

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Answered: 114 Skipped: 19



ANSWER CHOICES	RESPONSES	
Yes	27.19%	31
No	72.81%	83
TOTAL		114

Figure 24: *Distribution of results for survey question 19: Has your organisation experienced competition with other DPULOs?*

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Question 20. Does your organisation consider it ethically acceptable to undertake charitable fundraising (for instance: street collections, telephone donations or similar activities)?

In literature review 1 (chapter 2), French and Swain (2004) discussed the personal tragedy theory of disability where disabled people were seen by society as being weak, vulnerable and in need of help. Barnes (1991) claimed that such a view resulted in the practice of charitable fundraising to reconcile society's fear of disability and to satisfy the need to help disabled people. In my view, the two CEOs in the stage 1 interviews who believed that charitable fundraising was ethically unacceptable were clearly opposed to such discriminatory practices. In addition, although one other CEO recognised the ethical dilemma of these practices, he/she was still willing to sanction the undertaking of such charitable activities. As the chairman of a DPULO, I was also opposed to the practice of charitable fundraising within my own organisation as I felt it reinforced society's perception that disabled people were weak and vulnerable (Hunt, 1966).

In light of the discussions in literature review 1 (chapter 2), the comments by the three CEOs and my personal experience, I felt that the issue of charitable fundraising warranted further investigation within the full population of DPULOs.

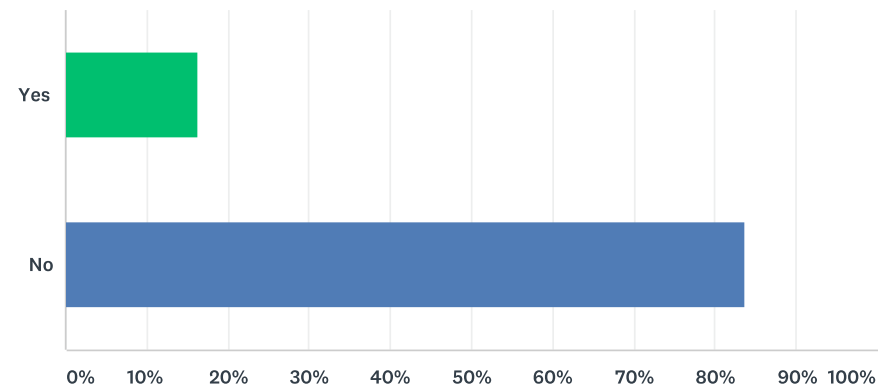
Therefore,

the intention of question 20 was to ask the CEOs to indicate if their organisation considered it ethically acceptable to undertake charitable fundraising. A total of 116 of 133 CEOs responded to this question and their responses are shown in figure 25.

The responses indicated that 97 respondents (83.6%) of the organisations did not undertake charitable fundraising as they believed it to be ethically unacceptable. These results suggested that a significant majority of the organisations would not accept funding from such sources. However, the results also indicated that a small minority (19 respondents or 16.4%) of the organisations did undertake charitable fundraising. However, it was not known if these organisations had ethical concerns or not about undertaking such activities.

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Answered: 116 Skipped: 17



ANSWER CHOICES	RESPONSES	
Yes	16.38%	19
No	83.62%	97
TOTAL		116

Figure 25: *Distribution of results for survey question 20: Does your organisation consider it ethically acceptable to undertake charitable fundraising (for instance: street collections, telephone donations or similar activities)?*

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Question 21. Please provide any additional comments about the current challenges and/or future opportunities for your organisation?

During the analysis of the stage 1 transcripts, it became clear to me that the 12 CEOs were aware of the challenges they faced and recognised the importance of creating new opportunities that might ensure their organisations' survival. Six key challenges were identified during the stage 1 analysis: financial constraints; contract procurement; capacity; competition; board/staff recruitment and retention; and board/staff skills. The stage 1 analysis also identified three key opportunities that might ensure organisational survival: traditional independent living services; innovative independent living services; and partnership working. Therefore, survey question 21 was formulated to investigate if the CEOs from the wider population of DPULOs had a similar perspective to those interviewed in the stage 1 research. In addition, the intention was to encourage the CEOs to express other views that had not been previously identified. A total of 55 of the 133 CEOs responded to this question.

All of the six key challenges that were identified in the stage 1 research were in some way reflected in the responses to question 21. However, it was apparent that comments about financial constraints were particularly prevalent. Also, there were additional challenges mentioned that I considered to be of importance: there was inadequate government support for DPULOs, in particular mismanagement within the ODI Strengthening DPULO Programme; national government did not appreciate the needs of disabled people; and there was a fear that the ideology of austerity disproportionately affected disabled people and their organisations.

In contrast to the responses about challenges, there were very few responses that could be interpreted as being future opportunities for the organisations involved, although partnership working was specifically mentioned. However, in addition to those that emerged from the stage 1 research analysis, the following opportunities were mentioned in the responses to question 21: the belief that their organisation was well run; and the expansion of the organisation's geographical/customer base would result in the ability to bid for more contracts. Some of the CEOs also indicated that although being a DPULO was a challenge, the inherent values of a DPULO presented an opportunity for future survival.

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In conclusion, my overall perception of the responses was that the CEOs appeared to suggest that they believed their organisations were of value to disabled people and could provide a unique high quality service. However, they felt that they were constrained by a belief that their DPULOs were unable to fulfil required contractual responsibilities and that they suffered through the financial pressure caused by the marketisation of support service contracts, particularly by local government providers.

7.6 Summary

In this chapter, I have presented the findings from a survey completed by a total of 133 CEOs from DPULOs located in the UK. The primary purpose of the survey was to present, in the form of questions, key findings from stage 1 of the research to a wider group of CEOs. The survey was designed to investigate if the findings resonated with a wider population of DPULOs.

As in stage 1 of the research, the survey explored areas such as the key characteristics of DPULOs and the challenges they faced as a result of the programme of austerity that was triggered by the financial crisis that started in 2008. The majority of responses from the CEOs endorse my earlier findings but also added further nuances and highlighted some of the other challenges faced by the CEOs and their organisations.

The survey responses indicated that there was a major expansion in the establishment of DPULOs from 1980 onwards. This suggested that, in spite of the economic and political challenges they have faced, the number of DPULOs has steadily increased since their inception in the late 1970s. The CEOs responded from all regions of the UK, the majority in England, and a smaller number from Scotland, Wales and Northern Ireland.

The values espoused by DPULOs that were highlighted by the CEOs in the previous chapter were reflected in the survey findings. Indeed, the majority of CEOs stressed that independent living and the social model of disability were important values for their organisations.

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However, in contrast to earlier findings, equality was the value category that received the highest number of responses from the CEOs in the stage 2 survey. This finding was considered to be particularly important as the values espoused by the early UK disability movement had evolved and were more focused on the needs of disabled people in areas such as equality. Values such as the social model of disability appeared to have declined in importance for the CEOs as disabled people moved closer to achieving equality through the application of independent living services. While this finding was not explicitly expressed by the CEOs in the stage 1 findings, it formed the sub-text of many of the themes. For example, in relation to recruitment challenges where CEOs alluded to shifts in the expectations and attitudes of some disabled people, particularly the younger generation, who may be seeking inclusion in mainstream employment rather than in organisations focused on disability support. The strongly held objections to charitable fundraising highlighted by the CEOs in the last chapter were also echoed in the survey responses with 83.6% of organisations that believed it to be ethically unacceptable.

The question of what it means to be a DPULO in the 2000s was also apparent in both stages of the research. The ODI's sometimes rigid criteria regarding being led and controlled by disabled people (stated as 75% of board members being disabled) was also challenged in both stages of the research. For example, the CEOs clearly identified as being a DPULO but did not necessarily adhere to the stated minimum percentage. The CEOs also appeared to be confused by the rather vague terms used by the ODI. For example, 'a commitment to' employing disabled people and volunteers rather than a requirement to. As with the CEOs involved in the stage 1 interviews, the participants in the survey showed an overwhelming commitment to the recruitment of disabled people as staff, volunteers and board members.

The findings in this stage of the research identified similar challenges for DPULOs as that of stage 1, namely: cuts in some funding; struggling to find time to write bids; and the ability to plan strategically. The CEOs also identified gaps in their organisations' knowledge base relating to professional and business skills such as marketing; commissioning and procurement; and income generation. However, there were both original and nuanced findings in this area. For example, while there was a reduction in funding to DPULOs from local and national government contracts, this was less dramatic than those identified in the stage 1 research.

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There was also an increase in funding to DPULOs from local and national government grants and from foundations and other grant bodies, these increases contradicted the conclusions reached in the Inclusion London (2012) report.

The majority of DPULOs had governance processes such as appraisal; training and development; and feedback mechanisms. However, only a small number of DPULOs were registered for a QMS. This was probably because such quality systems were notoriously expensive to introduce and maintain.

A new finding from the wider population of DPULOs was that just over half of the CEOs who responded to the survey managed organisations that under the NCVO (2016) definition were considered as being micro or small. While there were some strengths in being small, such as the ability to respond to problems quickly, these organisations were more vulnerable to any falls in funding. Given the economic climate at the time of undertaking this research, just as austerity measures were taking hold, coupled with the majority not receiving any revenue from investments and legacies, it was perhaps not surprising that the overall findings reflected the number of DPULOs involved in commercial activities. However, the survey findings still showed that approximately half of DPULOs failed to derive any income from selling their assets and services to other organisations. Worryingly, 66% of the CEOs had used their financial reserves to support the activities of their organisations. This might place such DPULOs at risk of closure. Unlike the stage 1 findings, less than a third of organisations faced competition for contracts from other DPULOs. However, the overall solution for the issue of competition from other organisations within local authority contract procurement processes was the introduction of alternative models such as partnership working and the expansion of their geographical and customer base.

Overall, the disproportionate impact of austerity on DPULOs was highlighted as was the potential pitfalls in the ODI's criterion and its interpretation by different CEOs. This did not appear to fully capture the complexities of the changing shape of DPULOs and the disability movement as a whole.

The next chapter draws on the findings from both the stage 1 semi-structured interviews and the stage 2 survey to discuss the issues in relation to my research questions and the existing key literature in the field of disability studies.

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CHAPTER 8. DISCUSSION

8.1 Introduction

In the last chapter, I presented the data from a survey of 133 CEOs from UK-based disabled people's user-led organisations (DPULOs). The data was presented using a combination of graphical and tabulated results. In addition, an analysis of the main findings from the survey were presented.

In this chapter, I will discuss the findings from my semi-structured interview transcripts and the survey data in relation to the existing body of knowledge detailed in the two literature review chapters (see chapters 2 and 3). The concepts of 'power' 'values' and 'knowledge' (SOL, 2009, cited in Bott, Sweeny and Watts, 2013) will form the basis of an investigation into the key characteristics and the challenges faced by DPULOs. These concepts will also be used to identify the factors, that I suggest, based on the findings of my research, might support the future security of DPULOs. Where appropriate, I will reflect on my own lived experience as a disabled person; as the chairman and trustee of a DPULO; and as a full member of a DPULO.

In undertaking this investigation, I return to the three research questions detailed in my methodology chapter (see chapter 4):

1. What factors influenced the establishment and development of DPULOs?
2. What are the key characteristics of and challenges for DPULOs?
3. What factors might support the future security of DPULOs?

In the methodology chapter (see chapter 4), I discussed how Mertens (2012) considered power relationships as key factors in studies undertaken within the transformative paradigm. I also considered that a key outcome of the research was to highlight the identified power differences between disabled people and society in order to influence change in DPULOs. Consequently, the discourse related to the power relationships between DPULOs and society will be reflected in this discussion.

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8.2 The factors that influenced the establishment and development of DPULOs

The intention of this section is to identify the key factors in the establishment and development of DPULOs from the mid-1970s.

8.2.1 DPULOs established in the 1970s and 1980s

Those organisations established for the benefit of disabled people prior to 1990 were primarily formed as campaigning groups to 'challenge the established medicalised, individualistic, and tragic disability discourses then held as accepted norms by society in general' (Blackmore and Hodgkins, 2012, p.4). The campaigning ethos that was adopted by these organisations was informed by concepts such as those espoused by the Union of the Physically Impaired against Segregation (UPIAS) (1976), the International Year of Disabled People (IYDP) (Taylor, 1981; 1993), the Independent Living Movement in the USA (ILM) (Evans, 2003; Pridmore, 2006) and the social model of disability (Oliver, 1983, 1990a).

My research has shown that some of the organisations created in the 1970s and 1980s were not in fact established as DPULOs but were formed and controlled by non-disabled people for the benefit of disabled people. This demonstrated that the institutions and interventions of the 19th century still existed in the lives of disabled people into the 1980s (Braddock and Parish, 2001).

During the 1980s, some disabled people became disillusioned with those organisations that were run and controlled by non-disabled people because they wished to achieve choice and control over their own lives (UPIAS, 1976; Barnes, 2007). This required a change in the controlling influence of those organisations run by non-disabled people and/or the establishment of new organisations. My research demonstrated that this type of change did indeed occur and identified instances where, during the 1980s, the control of organisations run by non-disabled people switched to disabled people and those organisations became DPULOs. This finding supported the claim made by Blackmore and Hodgkins (2012, p.4) that DPULOs 'were, and are, created, and controlled by disabled people in response to needs and wants, defined by themselves, for themselves'. This showed that disabled people were intent on the development of a political movement that supported their claim for equality and self-determination within society (Blackmore and Hodgkins, 2012).

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However, my research also identified that, in one case at least, there was a level of opposition by non-disabled people to disabled people assuming control of their own organisations.

In contrast, my research demonstrated that there was an approximately three-fold increase in the number of DPULOs established in the 1980s when compared with the number established in the 1970s (see chapter 7, survey question 1). In general, the DPULOs established in the 1980s were created by groups of disabled people who had become disenchanted with the discrimination they suffered within society. Those organisations established in the early 1980s were influenced by the concepts adopted by the disability movement in the UK and, particularly, the principles developed in the USA by the ILM (Evans, 2003; Pridmore, 2006). Further organisations were then established in the UK, based on the cross-fertilisation of knowledge and ideas developed in the organisations formed in the 1970s and earlier in the 1980s. These factors contributed to the expansion in the numbers of DPULOs during the 1980s, but because of the discrimination experienced by disabled people at the time these DPULOs were primarily focused on campaigning for disability rights. The analysis of the interview transcripts of the organisations established as DPULOs in the 1980s suggested that these organisations mirrored these principles. However, these organisations were only influenced by some of the concepts espoused by the disability movement, including the social model of disability (Oliver, 1983; 1990a) and the principle that disability organisations should be user-led (Woodin, 2006; Maynard Campbell, Maynard and Winchcombe, 2007).

The Disability Discrimination Act (DDA) (1995) (DDA, 1995) was introduced in order to legislate against the perceived discrimination of disabled people by society (Oliver and Barnes, 2006; Blackmore and Hodgkins, 2012). However, this legislation was opposed by some activists and their DPULOs as it was believed that full civil rights for disabled people were not adequately addressed (Oliver and Barnes, 2006). Consequently, such organisations continued to pursue the campaign for disability rights, which was their primary objective when they were first established in the 1980s. In reviewing the interview transcripts, I have concluded that the CEOs from the DPULOs established in the 1980s were, by using emotive language in a similar way to that of early disability activists, indicating that their organisations remained as, primarily, campaigning organisations for the rights of disabled people.

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Therefore, these organisations remained dedicated to the original principles of the UK disability movement.

Subsequently, further government initiatives in disability policy development, including, for instance, the Community Care (Direct Payments) Act (1996) (Barnes, 2007) and the Improving the Life Chances of Disabled People policy document (2005) (PMSU, 2005) encouraged some DPULOs to operate local authority direct payment services in order to support independent living for disabled people. There was no specific evidence in my interview transcripts to indicate that two of the DPULOs established in the 1980s offered any direct payment services to their clients. However, one of the CEOs alluded to the involvement by their DPULO in the process of direct payment support in the areas of personal budgets, advice and guidance and payroll services (see chapter 6). The interview transcripts indicated that this organisation had experienced a number of changes in senior personnel since its establishment in the early 1980s and, although it fundamentally remained a campaigning organisation, the CEO had ensured that his/her working relationship with the local authority was mutually beneficial (see chapter 6). In addition, there were concerns expressed regarding the marketisation of such local authority services and the subsequent financial constraints experienced by DPULOs in general (Oliver, 2013). These comments bring into question the claim by Blackmore and Hodgkins (2012, p.8) that direct payment contracts 'have contributed to significant growth and sustainability' for organisations run and controlled by disabled people.

The changes in government policy concerning disabled people introduced after the 1980s were factors that influenced the range of services offered by DPULOs. However, I concluded that those DPULOs established in the 1980s remained dedicated to their founding principles. Consequently, these principles appeared to have acted as a barrier to change and resulted in the promotion of those services that they believed would best support their clients. The analysis of the interview transcripts supported this position and indicated that the services supplied reflected some, at least, of the 12 needs of independent living (Davis and Mullender, 1993; Evans, 2003).

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The transcripts also indicated that funding for some of these services was provided from local authority sources. However, one of the CEOs acknowledged that his/her organisation recently lost all their capital funding from the local authority and were having to fund all support services from existing financial resources. As a result, this particular CEO was antagonistic and critical of the perceived intentions of the local authority.

In conclusion, my research has demonstrated that the DPULOs established in the 1980s as campaigning organisations have remained true to their founding principles. This has resulted in their rejection of some of the government's financial solutions intended to promote equality and independent living for disabled people. While these organisations were established as a result of the principles espoused by the UPIAS (1976, p.4), in reality they only fulfilled principle 'a', namely that:

'disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation'.

8.2.2 DPULOs established in the 1990s

Earlier in this chapter, I concluded that factors such as the perceived inadequacies of the DDA (1995) (Oliver and Barnes, 2006) influenced some activists and their organisations established in the 1980s to continue the campaign for disability rights. The analysis of my interview transcripts indicated that the values of organisations established in the 1980s became fundamental parts of the philosophy of DPULOs formed during the 1990s. This demonstrated that the cross-fertilisation of knowledge and ideas was not only reflected in the development of DPULOs in the 1980s but also occurred between these existing organisations and those established in the 1990s. Therefore, the campaigning ethos of those organisations established in the 1980s was retained within DPULOs formed in the early 1990s.

However, the introduction of government initiatives such as the Community Care (Direct Payments) Act (1996) encouraged a more pragmatic approach by DPULOs to the perceived discriminatory practices towards disabled people within society. This resulted in a change of focus by those DPULOs formed early in the 1990s from a campaigning ethos to the provision of direct payment services. This change in focus also triggered an expansion in the number of new DPULOs.

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The interview transcripts confirmed that those organisations established as DPULOs after 1996 were formed to specifically support local authorities in the provision of direct payment services. In addition, one CEO stated that his/her organisation was first established as a peer support group early in the 1990s but became a DPULO in 1998 in order to undertake a direct payment contract on behalf of the local authority. Therefore, the introduction of direct payment services caused the campaigning ethos of the earlier established DPULOs to be marginalised by what was perceived to be a more practical method of obtaining independence, choice and control for disabled people.

In contrast to those organisations established in the 1980s, my research does support Blackmore and Hodgkins (2012, p.8) in that the Community Care (Direct Payments) Act (1996) 'contributed to significant growth and sustainability' for DPULOs created in the 1990s. Therefore, I have concluded that the introduction of direct payment services contributed to the approximately one-third increase in the number of DPULOs established in the 1990s when compared with the number established in the 1980s (see chapter 7, survey question 1). However, these organisations were not only influenced by the introduction of direct payments but were also attracted by the increased financial support made available by local authorities to operate independent living services (Blackmore and Hodgkins, 2012). This suggested that local authorities maintained a controlling influence over those organisations operating these contracts in terms of their financial wellbeing and the services they offered to their clients (Borkman et al., 2009).

The introduction of some subsequent government initiatives such as the Improving the Life Chances of Disabled People policy document (PMSU, 2005) promoted the benefits of independent living for disabled people and influenced the implementation of personal budget services within DPULOs. Those DPULOs that failed to respond to these changes were further marginalised through their continuing adherence to a campaigning ethos. The analysis of my interview transcripts indicated that the services supplied by those organisations established in the 1980s were adapted and new ones introduced so that the whole process of applying and managing independent living services could be consolidated with a local authority operating in partnership with a single DPULO.

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Consequently, my research supported the claim by Blackmore and Hodgkins (2012, p.24) that those DPULOs that embraced such partnerships became 'service delivery structures' and 'entered into contractual relationships with their local authority, and have consequently moved from being agents provocateurs, campaigning for change, to become trusted Local Authority allies'. Research on the third sector consistently shows that government funding of innovative service user-based organisations is a two-edged sword (Felton, 2005; Rose et al., 2016). Funding can provide stability and credibility for user-led organisations (ULOs) but their values tend to be antithetical to the bureaucratic and 'professionalised' models on which most government services are based. As Borkman et al. (2009) warned, government funding can threaten to co-opt, dilute the value and compromise the philosophy and practice of ULOs.

In conclusion, my research has indicated that DPULOs established in the 1980s were formed by disability activists primarily as campaigning organisations. In contrast, those DPULOs established in the 1990s were formed as a result of government initiatives that promoted independent living services to improve the lives of disabled people. While campaigning activities influenced local and national government in the way that services for disabled people were developed and provided, differences in ethos remain between DPULOs established in the 1980s and those established in the 1990s. Those DPULOs that have remained as campaigning organisations were averse to becoming involved in formal financial relationships with local government agencies. However, those DPULOs that have successfully formed partnerships with local authorities fulfilled the criteria of the UPIAS (1976, p.4) principle 'a' and have also satisfied the principles 'b' and 'c', namely that:

'disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people'.

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8.2.3 DPULOs established in the 2000s

The analysis of the interview transcripts indicated that government initiatives continued to support the establishment of DPULOs during the 2000s. In some cases, the local authorities took an active role in the process of establishment of DPULOs within their area of jurisdiction by providing financial and administrative support.

The interview transcripts also indicated that the values of organisations established in the 1980s remained as key principles for DPULOs formed during the 2000s. There was a further cross-fertilisation of knowledge and ideas from DPULOs formed prior to 2000 and those subsequently established. Consequently, the DPULOs established in the 2000s still considered concepts such as the social model of disability (Oliver, 1983; 1990a) and the principle that disabled people were entitled to independence, choice and control in their lives (UPIAS, 1976; Barnes, 2007) to be key values for their organisations. However, my research showed that the need to campaign for disability rights by these organisations became of secondary importance to the principle of achieving equality through independent living for disabled people (see chapter 7, question 6).

The DPULOs created in the 2000s had been established to provide similar services to those established in the 1990s. This was because they have become policy-reactive as a result of government initiatives to improve independent living for disabled people (Blackmore and Hodgkins, 2012). Services such as those that provided independent living for disabled people were set up through contracts from the organisations' local authorities. In one case at least, a DPULO was specifically established to provide a voice for disabled people during the commissioning, procurement and monitoring of local authority services as part of a hub-and-spoke consortium of DPULOs and other similar organisations (Bott, Sweeny and Watts, 2013; Williams, 2014). However, the overall purpose of the consortium was to support the local authority in the delivery of independent living services for disabled people. The interview transcripts suggested that, as a result of the introduction of the Improving the Life Chances of Disabled People policy document (PMSU, 2005), there was an increase in the number of DPULOs created towards the end of the 2000s. In contrast, the survey analysis showed that the rate of creation of DPULOs in the 2000s was slightly lower than the rate of creation that occurred during the 1990s (see chapter 7, survey question 1).

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In addition, the survey demonstrated that the rate of establishment of new DPULOs dropped significantly after 2009 (see chapter 7, survey question 1). This apparent reduction could be as a result of factors such as: a critical mass of DPULOs had been created; amalgamation of DPULOs and other similar organisations; and the beginnings of financial austerity.

One of the recommendations of the Improving the Life Chances of Disabled People policy document (PMSU, 2005) was that, where feasible, disabled people should have access to the job market and the ability to obtain paid employment. There was evidence within the transcripts that the DPULOs established in the 2000s were developing structures to facilitate compliance with this recommendation. For instance, of those interviewed, one of the DPULOs created towards the end of the 2000s supported the development of small independent businesses that were specifically designed to provide training and employment opportunities for disabled people. The expectation was that disabled people would obtain the relevant knowledge and skills to eventually secure employment within external organisations.

Therefore, I have concluded that DPULOs established in the 2000s have fulfilled the criteria of the UPIAS (1976, p.4) principles 'a', 'b', and 'c' (see section 8.2.2 above). In addition, some of these DPULOs demonstrated that the employment and training services they offered to disabled people provided a solution to the social oppression highlighted by the members of the UPIAS, namely that:

'... the impoverishment of physically impaired people arises out of the fact that, as a group, we are excluded from the mainstream of social activities. In the final analysis the particular form of poverty principally associated with physical impairment is caused by our exclusion from the ability to earn an income on par with our able-bodied peers, due to the way employment is organised. This exclusion is linked with our exclusion from participating in the social activities and provisions that make general employment possible' (UPIAS, 1976, p.14).

However, the research identified that the DPULOs established towards the end of the 2000s had not yet fully formalised their structures and services. Consequently, significant investment might be required in order that these organisations could realise their founding principles.

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8.3 The key characteristics of and challenges for DPULOs

8.3.1 Introduction

The intention of this section is to investigate the key characteristics of and challenges for DPULOs. The outcomes of this investigation will form the basis for identifying the factors that might support the future security of DPULOs. This process will be undertaken through the investigation of the power, values and knowledge inherent within DPULOs and their inter-relationships.

8.3.2 The characteristics of DPULOs

The characteristics of ULOs as described by Shaping Our Lives (SOL) were 'power', 'values' and 'knowledge' (SOL, 2009, cited in Bott, Sweeny and Watts, 2013) (see literature review 2 (chapter 3)). The investigation of these three characteristics and their inter-relationship was a key part of this research and were dominant overarching themes in the empirical findings, particularly in the stage 1 semi-structured interviews.

The Office of Disability Issues (ODI) incorporated the principles of these three characteristics in their definition of a DPULO (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). The intention of the ODI was to create a standard for organisations that would be funded by local authorities and other government agencies to provide services to disabled people (ODI, 2011, cited in Bott, Sweeny and Watts, 2013).

8.3.3 Power

The concept of power is a contested one (Felton, 2005), with dominant theories related to how power is distributed (pluralistic theories), how power is concentrated (elite theories) and the relationship of power to class and economic power (Marxist theories). Inherent within the ODI's definition of a DPULO were the principles that organisations were run and controlled by disabled people and had a board membership of a minimum of 75% disabled people (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). The analyses of the interview transcripts and the survey responses indicated that a clear majority of the organisations involved in this research could be considered as DPULOs under the ODI's definition (ODI, 2011, cited in Bott, Sweeny and Watts, 2013; Turnbull, 2012).

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This research demonstrated that DPULOs had serious concerns in the areas of, for instance: financial constraints; contract commissioning; and competition from other organisations (see chapters 6 and 7). These areas of concern related to the application of external power over which individual DPULOs had no control. Therefore, it was apparent that the concept of power inherent in the ODI's definition of DPULOs only applied internally to the organisations. Consequently, it can be concluded that the ODI's definition was deficient in that the impact of external power forces on DPULOs was not formally recognised.

A pluralist understanding may be helpful here. According to Felton (2005), a distinction is often made between 'insider' groups who have access to the establishment and who are able to work closely with central and/or local government, and 'outsider' groups who either are less powerful because they do not have easy access to influential people and structures inside policy machinery or who choose to remain on the outside so as not to compromise their ideals.

During the 1990s, there was an increase in partnership working between local authorities and DPULOs in the provision of independent living services for disabled people (Blackmore and Hodgkins, 2012). This suited both parties as the local authority was able to work with an organisation that was familiar with the requirements of disabled people, and the DPULO itself received the necessary funding to remain viable. While the balance of power rested with the local authority because they held the funds, there was interdependence between the two organisations. However, it can be concluded that, although there were external power differentials, the impact between local authorities and DPULOs was inconsequential as the association was mutually beneficial.

This type of relationship developed and was strengthened in the 2000s, and the successes were recognised in the Improving the Life Chances of Disabled People policy document (PMSU, 2005). This document recommended that there was a continuing development of the programme of co-operation between local authorities and DPULOs. The resulting processes formalised and further strengthened these relationships; however, this appeared to have created a paradox.

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While the award of contracts to DPULOs gave them financial stability for at least the period of the contract, requirements such as quality standards, performance evaluation and prudent financial management resulted in power over the DPULO remaining with the local authority. In consequence, this affected the DPULOs' ability to effectively campaign, particularly against those local authorities for whom they were providing contracted services (Borkman et al., 2009). Examples of this paradox were identified within the interview transcripts. In addition, one of the CEOs stated that the evaluation and monitoring requirements of contracts were such that his/her organisation was unable to comply as suitable resources were unavailable. This inability to comply resulted in the total withdrawal of the DPULOs' core funding and demonstrated that in this case, power rested solely with the local authority (see chapter 6).

As a result of the programme of austerity triggered by the financial crisis in 2008, funding of local authorities by central government entered a period of severe financial restraint. This forced local authorities to reduce their spending. To support these reductions local authorities created a market for some of their services, particularly those provided to disabled people through the provision of contracts with DPULOs. The creation of this market enabled other organisations, including those from the commercial sector, to enter the procurement process in competition with locally based DPULOs. From a financial perspective, the local authorities were therefore able to exert their power over all the organisations within the bidding process. In addition, power differentials developed between the other organisations within the bidding process and the local DPULOs. Better resourced organisations were therefore more powerful than these DPULOs and were, consequently, more likely to be successful in the bidding process. The research demonstrated that local DPULOs felt threatened by the power held by larger competitors and were particularly concerned about losing the contract-bidding process to such organisations (see chapters 6 and 7). In addition, the research showed that some local DPULOs had indeed lost contracts to other organisations (see chapters 6 and 7).

Therefore, it can be concluded that, while internal power - based on disabled people being in control of DPULOs - remained, the effective external power was controlled by local authorities and other organisations (Felton, 2005).

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8.3.4 Values

While there are also contested definitions of values, Blake et al., (2006, p.13) suggested that 'if the third sector is about something more than not for profit, we need to define it in terms other than its relationship to money'. Indeed, Blake et al. (2006) argued that values are key, listing among other things: empowering people; pursuing equality; making voices heard; and transforming lives. Macmillan (2012, p.8) noted that The National Council for Voluntary Organisations (NCVO) has sought to differentiate and distinguish the values in the sector, focusing on ideas of added value, distinctive value, and full value (Bolton, 2003).

Consequently, DPULOs, as part of the wider service user movement and development of ULOs, can be seen as a distinctive part of the third sector in relation to their values. Jochum and Pratten (2008, p.12), in their empirical research into values in the third sector, concluded that while distinctiveness is not necessarily a general feature of the third sector in relation to values, this is a contingent dimension that can occur where values are enacted, and that by 'living their values voluntary and community organisations can strongly differentiate themselves from the private and public sectors and in doing so maintain a distinctiveness that is likely to be increasingly important in difficult times'.

During the 1980s, the UK disability movement adopted the values introduced by organisations such as the UPIAS (1976) and the independent living movement in the USA (Evans, 2003; Pridmore, 2006) (see literature review 1 (chapter 2)). These values included: independent living (UPIAS, 1976; Barnes, 2007); the social model of disability (Oliver, 1983; 1990a); and the principle that disabled people's organisations should be user-led (Woodin, 2006; Maynard Campbell, Maynard and Winchcombe, 2007) (see literature reviews in chapters 2 and 3).

The analysis of the interview transcripts indicated that independent living and the social model of disability were identified by the CEOs as important values for their organisations (see chapter 6). In contrast, the survey results demonstrated that these values were mentioned less frequently than the results of the interview transcripts would suggest. However, the survey showed that the concept of equality was more important to DPULOs than any other value, including those of the social model and independent living (see chapter 7, question 6).

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The interviews were based on a semi-structured design; consequently the CEOs were able to explore a deep range of perspectives on the values espoused by their organisations. In contrast, the respondents to the survey were asked to provide, in effect, a snapshot of the values that were important to their organisation at a single point in time. As the successful implementation of the values inherent in the social model of disability and the principle of independent living would result in equality for disabled people within society, it could be inferred that the survey respondents were presenting a more practical perspective than that of the interviewees.

As mentioned, the principle that DPULOs should be user-led was adopted as one of the values espoused by the UK disability movement. Subsequently, the ODI incorporated this principle into their definition of a DPULO (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). The ODI definition requires organisations to be run and controlled by disabled people and have a board membership of a minimum of 75% disabled people in order to be considered as DPULOs (ODI, 2011, cited in Bott, Sweeny and Watts, 2013).

The analysis of the interview transcripts provided limited evidence that the CEOs considered being user-led to be one of the key values of their organisations (see chapter 6). However, the membership criteria and the composition of their boards demonstrated that the organisations, apart from one exception, could be considered as DPULOs under the ODI's criteria (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). In the case of this one organisation, the board had extended the membership and board criteria to include a majority that consisted of disabled people and their carers. The CEO of this organisation indicated that disabled people and their carers were considered to be users of the services provided and therefore felt that his/her organisation was user-led. However, the CEO conceded that some disability activists would disagree with his/her opinion. In addition, this organisation would not fulfil the ODI's definition to be considered a DPULO (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). However, it was apparent that the principle of being user-led was a value embedded in the ethos of all the organisations involved in the interviews. The analysis of the interview transcripts also showed that some of the organisations were experiencing challenges with the recruitment of disabled people to their boards and their retention. This suggested that the value of being user-led in terms of board membership was becoming untenable.

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In contrast to those organisations involved in the interviews, the survey results demonstrated that approximately one third of the respondents stated that their organisation did not fulfil the ODI's requirement of having a membership of a minimum of 75% disabled people on their board. However, nearly all the respondents were actively attempting to recruit disabled people to their board (see chapter 7, question 4). These results reflected the analysis of the interview transcripts in that there appeared to be major difficulties in the recruitment of disabled people to DPULO boards. Therefore, it could be considered that there was a potential threat to the value that DPULOs should be user-led as currently defined by the ODI. This issue seems to have been addressed when the ODI introduced a new criterion that an organisation could be classed as a DPULO if it actively attempted to attain the requirements of the original three criteria (see literature review 2 (chapter 3)) (Turnbull, 2012).

The survey showed that the principle that disability organisations should be user-led was significantly less important as a value to the CEOs than equality, independent living, or the social model of disability (see chapter 7, question 6). This suggested that, from the perspective of the CEOs, the primary objective of their organisations was to improve the lives of disabled people. The requirement to be user-led was not considered to be of major importance to achieve this objective. Therefore, it can be concluded that the values espoused by the early UK disability movement had evolved and were more focused on the needs of disabled people in areas such as equality. Values such as the social model of disability appeared to have declined in importance for the CEOs as disabled people moved closer to achieving equality.

The value inherent within DPULOs that appeared to evoke the most passion and emotion amongst the CEOs was the concept of charitable fundraising (see literature review 1 (chapter 2)). The analysis of the interview transcripts identified two CEOs who believed that charitable fundraising was ethically unacceptable to their organisations (see chapter 6). In addition, one other CEO indicated that his/her organisation did undertake charitable fundraising but understood that such practices would raise ethical issues for the UK disability movement (see chapter 6). The survey results indicated that a clear majority of the respondents also believed that charitable fundraising was ethically unacceptable (see chapter 7, question 20).

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This suggested that the concept of charitable fundraising remained a contentious issue for the CEOs in terms of the personal tragedy theory of disability (French and Swain, 2004). However, there was no evidence in the research to indicate that the CEOs considered that they faced a potential loss of income for their organisations by not accessing these funding sources.

The values inherent within the ODI's definition of a DPULO can be considered deficient. The ODI criteria primarily defined the internal structures and values of DPULOs. These criteria did not consider the external values, such as equality and independent living that the CEOs considered necessary to improve the lives of disabled people. In addition, as the concept of charitable fundraising was ethically unacceptable to DPULOs, they would require other sources of income to effectively support their overall financial wellbeing.

8.3.5 Knowledge

The initial concept of knowledge within DPULOs was based on the philosophical values adopted by the UK disability movement in the early 1980s such as the social model of disability (Oliver, 1983; 1990a) and the principle that disabled people should achieve independence, choice and control over their lives (UPIAS, 1976; Barnes, 2007) (see literature review 1 (chapter 2)). This concept of knowledge within DPULOs was extended, in the view of Bott, Sweeny and Watts (2013), to include the direct lived experience of disabled people (see literature review 2 (chapter 3)). The knowledge inherent within the ODI's definition of a DPULO was based on the concepts espoused by the early UK disability movement. However, the knowledge gained from the direct lived experience of the disabled board members, staff, volunteers and membership was not included (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). Consequently, the ODI's definition of a DPULO can be regarded as both inadequate and surprising, as experiential knowledge has been viewed as the backbone of the user movement and much more able to meet the practical and everyday needs of disabled people (Borkman, 1976).

The type of knowledge gained in ULOs was what Borkman (1976, p.446) termed 'experiential knowledge' which is subjectively based; it is knowledge based on truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation or reflection on information provided by others.

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A critical feature of ULOs is that they are 'learning' together and building a collective knowledge base that remains in the group even after an individual leaves.

The difference between an individual's experience of a health or social condition and the type of collective knowledge built over time within ULOs tends to be much underestimated by professionals and policy makers, yet it is crucial in understanding how some ULOs and the service user movement more widely have come to redefine their situation or condition.

The introduction of the Community Care (Direct Payments) Act (1996) prompted local authorities to seek relationships with organisations that were familiar with the needs of disabled people. The knowledge held within DPULOs, together with their inherent values, suggested that such organisations would be suitable agents for this purpose. Consequently, these relationships resulted in the development and implementation of direct payment services for disabled people (Barnes, 2007).

An example of this type of relationship was identified in the analysis of the interview transcripts of those DPULOs established in the 1990s. In one case, the CEO stated that his/her organisation had been set up with help from the local authority to handle direct payment services. The CEO indicated that the direct payment contract was originally held by a rival organisation controlled by non-disabled people. The establishment of a relationship with the local authority resulted in control of the direct payment contract being transferred to the new DPULO. This suggested that the local authority felt that the knowledge concerning the requirements of disabled people that was held by the new DPULO would better serve the interests of their disabled clients. Subsequently, all of the DPULOs established in the 1980s managed independent living services for their local authority (see chapter 6).

The Improving the Life Chances of Disabled People policy document (PMSU, 2005) emphasised the importance that the knowledge held within DPULOs contributed to the establishment of the relationships with local authorities (Blackmore and Hodgkins, 2012). The document recommended that these partnerships be strengthened and detailed the kinds of services DPULOs could be awarded to improve independent living for disabled people (PMSU, 2005). The analysis of the interview transcripts indicated that 10 of the 12 CEOs had introduced at least some of the services recommended in the policy document (PMSU, 2005) under contracts granted by their local authority (see chapter 6).

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This suggested that the local authorities considered that the DPULOs had sufficient knowledge to undertake the required contract provisions on their behalf.

In the interview transcripts, one of the CEOs described the information and advice provided to clients as part of his/her organisation's personal budget service. In addition, other CEOs highlighted services such as peer support and advocacy in which the direct lived experience of their employees was used to enhance the quality of the support provided to the clients. This demonstrated that the CEOs were aware that knowledge gained from the lived experience of disability and involvement within the social care system was an essential component in understanding the needs of disabled people (see chapter 6) (Borkman, 1976).

The reduction in spending that was triggered by the financial crisis forced local authorities to modify their contract procurement processes, including those for disabled people. The analysis of the interview transcripts indicated that the CEOs considered that these changes created a market for independent living services. They were particularly concerned that larger, especially national competitors had greater financial stability than that possessed by locally based DPULOs. The CEOs indicated that these larger competitors were better able to compete on price than were their own organisations. This point was highlighted by two of the CEOs who stated that they were aware of local authority contracts where the emphasis had changed with the result that a lower contract price was more important than the quality of the service offered to disabled people (see chapter 6). While the larger organisations were able to win contracts on price, the CEOs intimated that these competitors lacked specific local knowledge and it was this that affected service quality. These practices mirrored those of my own local authority. As the chairman of a DPULO, my organisation was involved in the bidding process for local authority independent living contracts. The specification for one of these contracts was launched in 2012, after the introduction of local authority austerity measures and the market for independent living services. The priority for the local authority in this particular case was the price of the contract rather than the knowledge held by the competing organisations regarding the needs of disabled people. Therefore, my DPULO lost this contract to a rival from the commercial sector. This suggested that my organisation lacked the essential professional and business skills necessary to effectively compete in competitive tendering processes. This reflected the findings of my research.

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The analysis of the interview transcripts confirmed that the DPULOs lacked a different type of knowledge, the practical knowledge necessary to develop essential business and professional skills (see chapter 6). In addition, the survey results demonstrated that the skills that were lacking in the majority of the DPULOs were those required to effectively compete with other organisations in local authority procurement processes (see chapter 7, question 12). Approximately half of the respondents to the survey indicated that their organisation undertook activities that could in some way be considered commercial in nature. However, the deficiency of business and professional knowledge and skills within DPULOs affected their ability to develop commercial business activities that would compensate for the reduction in their income through the loss of local authority contracts to competitors.

The analysis of the interview transcripts indicated that five of the CEOs considered that they had developed commercial business activities on behalf of their organisations (see chapter 6). These business activities were based on existing assets and services that were being offered to external fee-paying customers. However, there was no evidence in the transcripts to suggest that income from these assets and services had compensated for the loss of local authority contracts (see chapter 6). This suggested that the lack of essential professional and business skills within these organisations had also had an impact on their ability to create innovative ways of producing income other than that from local government sources.

The ODI's definition of DPULOs was based on the values inherent within such organisations but lacked an understanding of the knowledge appertaining to the practical lived experience of disabled people. However, DPULOs also lacked the practical knowledge necessary to develop essential business and professional skills and were therefore unable to compete effectively in local authority procurement processes and develop the necessary commercial activities to compensate for their corresponding losses in income.

The concepts of 'power', 'values' and 'knowledge' as outlined by Bott, Sweeney and Watts (2013) and discussed above, tend to be presented as though they are distinct ideas. However, Borkman et al. (2009) considered them as interlinked: they saw ULOs as both symbolic and practical enactments of power.

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With traditional professional services, the client is subordinate and the act of helping is one way; the goals and direction of help are largely in the hands of the 'professional' and the knowledge on which services are provided is professional and based on education and credentials. In contrast, ULOs are by their very nature symbolic of the success of disabled people in affirming a range of hitherto denied abilities and services derived primarily from direct lived experience. Howie the Harp (mental health activist, cited in Riessman and Carroll, 1995, pp.125-126) captured the essence of a ULO compared to mainstream services:

'Everybody is equal in power; clients control their individual services, and nothing is done against their will. Clients control the agency in which services are provided; the consumers providing services are role models who understand what the clients are going through; clients are recognised as the 'real' experts... In any form of partnership or what is now often termed co-production therefore for there to be attempts at equality there needs to be both understanding and respecting the centrality of experiential knowledge and the values these give rise to.'

8.4 The factors that might support the future security of DPULOs

8.4.1 Introduction

This section will investigate the factors that might support the future security of DPULOs. This process will be undertaken through: my interpretation of the analysis of the semi-structured interview transcripts and the survey data; my lived experience as a chairman and trustee of a DPULO; and the insights I gleaned from the two literature review chapters.

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8.4.2 Power

This research identified that the ODI's definition of a DPULO was only based on the concept of internal power. It can be inferred that the ODI did not consider the external power deficit between DPULOs and other organisations such as local authorities, national charities and businesses from the commercial sector. Historically, while there were power deficits between DPULOs and other organisations, these were exacerbated through the austerity measures introduced following the financial crisis that started in 2008. These power deficits were highlighted as major challenges to DPULOs in areas such as financial constraints, competition and changes to contract procurement processes. This research has demonstrated that these power differences are likely to pose threats to the future security of DPULOs. Consequently, there is a requirement to readdress the balance of power that currently exists between DPULOs, local authorities and other organisations.

The analysis of the interview transcripts indicated that one of the ways of readdressing the balance of power currently held by local authorities and other organisations might be to instigate the formation of working partnerships between DPULOs. The CEOs suggested that working partnerships would enable their DPULOs to gain better access to the tendering process with local authorities, generate higher levels of income and eventually help to secure the future of their organisations (see chapter 6).

The interview transcripts identified a number of CEOs who had previously investigated the possibility of building working partnerships with other DPULOs. One CEO indicated that he/she had already discussed the creation of short-term partnerships with the CEOs of locally based DPULOs that would assemble when local authority contract bidding processes became available (see chapter 6). This suggested that these short-term partnerships would generate the necessary power to effectively compete with other organisations involved in local authority contract procurement processes. This suggested that the combined resources of a number of DPULOs that formed short-term partnerships to achieve their overall strategic objectives could be used to readdress the balance of power held by other organisations in the bidding process for local authority contracts.

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In addition, the casual nature of DPULOs coming together on a short-term basis would enable them to preserve their individual identities while contributing the necessary resources to empower the partnership as a whole.

One of the other CEOs indicated that he/she intended to investigate the possibility of forming strategic partnerships or joint ventures with other DPULOs (see chapter 6). The evidence in the interview transcripts to suggest that strategic partnerships or joint ventures would help to readdress the balance of power currently held by local authorities and other organisations was limited. However, the CEO indicated that the formation of this type of partnership might enable his/her organisation to gain access to larger numbers of disabled people (see chapter 6). This suggested that the main objective for this CEO in establishing strategic partnerships or joint ventures was to generate additional income through the wider pool of disabled people available to his/her organisation. The establishment of these partnerships might also contribute to the cross-fertilisation of knowledge and ideas between the organisations and result in the development of new strategies for the mutual survival of DPULOs. One of the other CEOs illustrated the mutual benefit of such partnerships. In this example, the CEO indicated that an established organisation might act as the lead partner in the delivery of a local authority contract while a new DPULO gained the necessary knowledge and experience to operate a future funding opportunity (see chapter 6). This suggested that some CEOs were not only interested in maintaining the future security of their own organisations but were also intent on supporting the continuing survival of DPULOs as a whole.

The final partnership model identified in the interview transcripts was a hub-and-spoke consortium of DPULOs and other similar organisations (Bott, Sweeny and Watts, 2013; Williams, 2014). The CEO of this DPULO indicated that his/her organisation's responsibilities within the partnership was to undertake the ancillary work that underpinned the commissioning and procurement processes associated with local authority contracts. In addition, the CEO stated that the other members of the consortium were jointly responsible for all the other activities that marked their success in securing local authority contracts (see chapter 6). This suggested that while the members of the consortium were responsible for individual aspects of the procurement process, the combined resources of all the partners helped to shift the balance of power away from the other organisations involved in the bidding process.

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Examples of the local authority contracts secured by the combined resources of the consortium included: independent living services, including personal budgets and payroll services; and the development of citizens hubs that provided information, advice and advocacy for disabled people (see chapter 6). In a similar way to other partnership models detailed in this section, the members of the consortium were able to preserve their individual identities. However, the CEO indicated that maintaining an individual identity while also having the responsibility of working within a consortium resulted in some capacity issues for his/her organisation (see chapter 6).

This suggested that small organisations with limited resources might find it difficult to work within partnerships where the emphasis was placed on the collective rather than the individual operation of the members. The survey responses demonstrated that just over half of DPULOs were classed as either micro or small voluntary organisations (NCVO, 2016) (see chapter 7, question 7). The survey results therefore indicated that these organisations might be reluctant to become involved as members of a hub-and-spoke consortium (see chapter 7, survey question 7). However, as the survey demonstrated that the size of the DPULOs varied from micro to major voluntary organisations (NCVO, 2014), there were opportunities for a range of different partnership models to be established in most areas of the UK (see chapter 7, survey questions 2 and 7). In addition, while the responses from Northern Ireland and Wales were significantly smaller (one and two responses respectively) there was still scope for similar partnership models to be introduced into these areas of the UK in the future (see chapter 7, survey question 2).

In conclusion, this research identified three partnership models that could be used by DPULOs to readdress the balance of power currently held by local authorities and other organisations within contract commissioning processes. The suitability of these models to the needs of DPULOs and the possible benefits of incorporating them into the structures of the organisations was discussed.

8.4.3 Values

The ODI's definition was based on the concept that DPULOs adhered to the social model of disability (Oliver, 1983; 1990a) and the principle that such organisations should be user-led (Woodin, 2006; Maynard Campbell, Maynard and Winchcombe, 2007).

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This definition could be considered deficient as it did not appear to recognise the value of equality (Blackmore and Hodgkins, 2012) and the principle of independent living (Barnes, 2007). Similarly, as in the characteristics of the concept of power, discussed earlier, these values were also considered to be external to DPULOs.

The analysis of the interview transcripts demonstrated that the CEOs believed that the social model of disability and the principle of independent living were key values to their organisations. The values of equality and the principle that DPULOs should be user-led were not stated explicitly by the CEOs. However, these values were found to be implicit within the comments made in their interviews (see chapter 6). The survey demonstrated that as disabled people moved towards equality through the application of independent living services, the principles espoused within the social model of disability appeared to become less important to DPULOs (see chapter 7, question 6). This suggested that the external values that emerged through this research were becoming more relevant to the CEOs of contemporary DPULOs and confirmed that the change from their organisations previous campaigning ethos was, for some, justified.

The research also confirmed that charitable fundraising was ethically unacceptable to DPULOs. Consequently, the CEOs were unable to benefit from a key source of income to support the continuing operation of their organisations. Therefore, it was considered that the apparent reduction in the importance of the principle that DPULOs should be user-led (according to the current ODI definition), and the justification for a value that placed DPULOs at a significant disadvantage compared to other similar organisations in terms of obtaining charitable funding required further investigation.

The analysis of the interview transcripts identified two key issues for the CEOs in preserving the user-led status of their organisations. One of the issues highlighted by the CEOs was the recruitment and retention of disabled people to serve on their management boards. This particular issue was discussed by one of the CEOs who stated that he/she felt it was always a struggle to find disabled people willing to sit on his/her management board. The CEO speculated that this was a result of a general level of apathy amongst disabled people.

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The CEO also indicated that because his/her organisation was based in a rural part of the country and public transport links were not good, disabled trustees would find it particularly difficult to travel to board meetings (see chapter 6). However, these comments failed to take into account other opportunities open to disabled people as a result of obtaining independence, choice and control in their lives such as increased levels of employment in mainstream organisations and the ability to use alternative methods of transport, for example, in a personal budget contract with their local authority (Blackmore and Hodgkins, 2012).

One of the CEOs related this point to the retention of disabled people as board members within his/her organisation. The CEO stated that three of the most senior posts on his/her board were held by disabled people who were in full-time employment. The CEO indicated that as a result, these three trustees found it increasingly difficult to attend official board events (see chapter 6). This demonstrated that the experience of equality achieved by disabled people as a result of their increased independence might mean that they could no longer be relied upon to serve on the boards of DPULOs.

There was no evidence in the interview transcripts concerning the possible solutions that could be put in place to reverse the issues related to the recruitment and retention of disabled board members within DPULOs. However, one CEO highlighted the issue of recruiting and retaining disabled employees within his/her organisation. The CEO indicated that although his/her organisation's policy was to interview all disabled applicants, he/she felt that they should always recruit the best person for the job (see chapter 6). This method could be applied to the recruitment and retention of board members within DPULOs. While this way of working might not preserve the user-led status of some DPULOs, the overall board might be strengthened with the addition of some non-disabled trustees. This appeared to have been the case with one of the DPULOs involved in the stage 1 research. The CEO of this organisation stated that his/her board had extended the membership and board criteria to include both disabled people and their carers (see chapter 6). While this arrangement resulted in the loss of the DPULO's user-led status in terms of the ODI's definition of a DPULO (ODI, 2011, cited in Bott, Sweeny and Watts, 2013), the CEO felt that a combination of both disabled people and carers as trustees strengthened the overall authority of the management board. In addition, the CEO indicated that as all the trustees used the DPULO's services, his/her organisation could still be classed as user-led.

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The other issue highlighted by the CEOs was the lack of professional and business skills within their management boards. One of the CEOs detailed the issues experienced by a disabled person who joined his/her management board but did not have the relevant knowledge and skills to be an effective trustee. The analysis of the interview transcripts indicated that DPULOs lacked knowledge and skills in areas such as governance; accountancy; and human resource management (see chapter 6). The survey responses extended the essential professional and business skills that were lacking in more than 50% of DPULOs to include: marketing and sales; legal; commissioning and procurement; and income generation (see chapter 7, question 12). This demonstrated that in order to move from campaigning organisations to service providers, DPULOs required a range of high-level professional and business skills. However, there was limited evidence in the interview transcripts to show how the CEOs could introduce these skills into their organisations.

In spite of this limited evidence, one of the CEOs indicated that he/she recently instigated the formation of a subsidiary trading company to sit alongside his/her organisations board of trustees. The board of this company included a number of non-disabled directors who had experience of impairment and the essential professional and business skills not available within the existing board of trustees. The two boards worked in conjunction to manage a range of independent living services on behalf of the organisation (see chapter 6). This demonstrated that the organisation was able to maintain the user-led status of a DPULO while increasing the range of professional and business skills available within the organisation (see chapter 6).

In addition, my own organisation instigated a different method of introducing professional and business skills into the board of trustees. The management board considered that maintaining the user-led status of the organisation was no longer viable and might even result in its eventual closure. Consequently, a new organisation was established that could appoint non-disabled as well as disabled people as directors. This enabled the new organisation to recruit board members from a wider pool of available talent within the local community who held the professional and business skills required by the organisation as well as being sympathetic to the values and experience inherent within DPULOs.

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Oka and Borkman (2011, p.16) introduced the concept of a practitioner as 'Self-help Supporter'; a professional, official, or anyone who is not a peer member of a self-help group or organisation but who 'respects the autonomy and integrity of the group and works as the members' wish'.

The interview transcripts indicated that only two of the CEOs were opposed to street collections or similar methods of fundraising to obtain money for their organisations (see chapter 6). In contrast, the survey showed that over two-thirds of the respondents suggested that their organisations were ethically opposed to the concept of charitable fundraising. However, there was no evidence in the interview transcripts to suggest that the CEOs had considered their potential loss in income as a result of being opposed to this type of fundraising.

One of the CEOs indicated that his/her organisation did undertake charitable fundraising, although he/she was aware that the UK disability movement was opposed to the practice (see chapter 6). This suggested that this CEO might have overlooked the potential ridicule his/her organisation faced from the disability movement as a result of having to raise money to secure the future of his/her DPULO. In addition, the CEO might be following the example of other charities that undertake a wide-range of fundraising activities to raise money for their organisations.

There was no evidence in the interview transcripts to indicate that the CEOs had introduced alternative methods of raising money from charitable sources. However, my own DPULO instigated measures such as sponsorship from UK and international businesses in return for the provision of experiential knowledge held by disability equality trainers within the organisation. This type of measure circumvented the issue of charitable fundraising highlighted by the majority of DPULOs in this research.

In conclusion, this research highlighted some of the solutions that could be put in place to change the emphasis of values, for example that DPULOs should be user-led; and that these organisations were opposed to charitable fundraising. These measures were considered to be appropriate for helping to support the continuing inclusion

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of disabled people on the boards of DPULOs; increasing the range of professional and business skills available to their boards of trustees; and providing additional income through alternatives to charitable fundraising.

8.4.4 Knowledge

The criteria within the ODI's definition of DPULOs did not demonstrate an appreciation of the experiential knowledge of disability held by the organisations' board members and employees. The wealth of knowledge within DPULOs about the lived experience of disabled people was vital in the development of independent living services in conjunction with local authorities. However, following the financial crisis in 2008, local authorities felt that this knowledge was of less importance within contracts for independent living services than were those of monetary considerations. This research demonstrated that in general, DPULOs lacked the essential professional and business skills necessary to compete within this new environment. Consequently, it was considered important to investigate how the necessary knowledge and skills could be introduced into DPULOs.

The government initiative that could have supported the development of the essential professional and business skills required by these organisations was the ODI's Strengthening DPULO Programme (DPULO Programme Team, 2016). One of the aims of the programme was to help support the future security of DPULOs (DPULO Programme Team, 2016) (see literature review 2 (chapter 3)).

However, there was no evidence in the research to suggest that the programme included the facility for the CEOs to apply for funding to improve the professional and business skills available within their organisations. In fact, the survey responses indicated that the CEOs felt that there was inadequate government support for their organisations, particularly within the ODI Strengthening DPULO Programme (see chapter 7, question 21). This finding supported my earlier assertion that the programme had been severely underfunded by the coalition government of Conservatives and Liberal Democrats (see literature review 2 (chapter 3)).

However, the analysis of the interview transcripts showed that in spite of this lack of funding, the organisations offered training and development opportunities to their employees, volunteers and board members. One of the CEOs indicated that his/her organisation provided a training budget to specifically support the professional

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development of the employees. In addition, one of the other CEOs highlighted the training and development opportunities that were open to the volunteers involved in his/her organisation (see chapter 6).

In support of these findings, the survey responses indicated that approximately two-thirds of the organisations offered similar opportunities to all members of their workforce (see chapter 7, question 14). This suggested that the CEOs understood the importance of training and development in the creation of a skilled workforce (see chapter 6). In addition, there was some evidence in the interview transcripts to demonstrate that the CEOs understood the importance of professional and business skills within their organisations. One of the CEOs highlighted the lack of marketing skills on his/her board of trustees. The CEO indicated that his/her organisation's marketing sub-committee was an adequate replacement until a new trustee with relevant skills could be recruited (see chapter 6).

The analysis of the interview transcripts highlighted some of the ways that the CEOs could recruit individuals with the essential professional and business skills required by their organisations. Two of the CEOs indicated that they bought-in the services of non-permanent staff who provided the knowledge and skills not possessed by their own organisations. Similarly, one of the other CEOs showed how the secondment of a temporary member of staff from the Department of Work and Pensions (DWP) with the appropriate management skills could support the development of his/her organisations' strategic objectives (see chapter 6). In these three cases, the CEOs recruited individuals with the specific skills to support the internal operation of their organisations. However, there is no reason why this method of recruitment could not be extended to the external professional and business skills required by DPULOs.

In addition, one of the CEOs highlighted the training and development opportunities that he/she received from the organisation's board of trustees. The CEO indicated that he/she was able to undertake a secondment to another organisation as part of the board of trustees' programme of continuing professional development for senior staff (see chapter 6). In a similar way to the examples provided earlier in this chapter, the secondment of senior staff to other organisations for the purposes of continuing professional development could be extended such that they could gain the professional and business skills required by their DPULOs.

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The interview transcripts also highlighted the professional manner in which some of the organisations managed the training and development opportunities available to their workforce.

One of the CEOs indicated that all members of staff within his/her organisation received an annual appraisal and monthly supervisory meetings. In addition, one of the other CEOs stated that his/her organisation recently introduced an appraisal scheme specifically aimed at his/her board of trustees (see chapter 6). The survey results indicated that at least two-thirds of DPULOs offered an appraisal scheme to their employees and volunteers. However, just one third of the organisations offered an appraisal scheme to their board of trustees (see chapter 7, question 13). This suggested that the majority of management boards had not considered their own training and development needs or the skills that were held by the trustees.

The analysis of the interview transcripts showed that two of the CEOs were aware of issues related to the training and development of their management boards. One of the CEOs indicated that he/she had just instigated a skills audit of his/her board of trustees. The CEO's intention was to provide a range of training events to improve the overall skill-base of his/her management board (see chapter 6). This suggested that the CEOs that had introduced measures to improve the skills of all members of their workforce were aware of the link between training and development and the ability of organisations to support the needs of their clients (NCVO, 2018).

Earlier in this chapter, the introduction of essential professional and business skills into DPULOs were considered to not only readdress the balance of power held by local authorities and other organisations but would also enable them to develop commercial business activities. The analysis of the interview transcripts indicated that out of the six CEOs who were in the process of developing innovative support services on behalf of disabled people, two intended to generate income for their organisations by offering these services to the local community. One of the CEOs stated that his/her intention was to extend the facility currently operated by his/her organisation that provided training for disabled people to enter the catering sector. The CEO indicated that he/she would offer services such as café facilities and sandwich rounds to the local community in order to generate income for his/her organisation (see chapter 6). This suggested that some CEOs were moving away

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from a reliance on local authority funding to a model where their organisations introduced a portfolio of services that would enable their DPULOs to generate income from a range of different sources. Therefore, such models could be used to support the future security of their organisations.

In conclusion, this research identified measures that could be introduced to improve the knowledge and skills held by the senior staff and board members within DPULOs. The introduction of essential professional and business skills into DPULOs would result in a change in the balance of power currently held by local authorities and other organisations. The introduction of professional and business skills would also enable DPULOs to generate income through a range of different sources including those of local authority contracts and commercial activities. This range of funding sources might therefore help support the future security of DPULOs.

8.5 Revisiting the conceptual framework

The conceptual framework developed earlier in this thesis (see: chapter 4, section 4.2) was designed to show the concepts and their related phenomena that had an impact on the operation of DPULOs. The structure of the conceptual framework came from a combination of the knowledge gained through my lived experience as a disabled person, as the chairman, trustee and member of a DPULO and the two literature review chapters.

When I reflected on the overall outcomes of the discussion chapter, I felt that there were clear links between the relationships within the conceptual framework and the findings from the two stages of research. The discussion chapter showed that a number of similarities existed between the concepts and their related phenomena outlined in the conceptual framework and the overall operation of DPULOs as detailed in the research outcomes. In both cases, there were reductions in national and local government funding, issues related to the marketisation of social care services and competition from other more business-oriented organisations which had an impact on the quality and range of services that DPULOs provided for their clients.

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However, the discussion chapter also highlighted a number of core findings concerning the challenges faced by DPULOs which were not prominent in the original framework.

Firstly, the research indicated that power shifts over time, but during economic austerity, 'value for money' is given priority over experiential knowledge, leaving DPULOs vulnerable. Secondly, some values remain consistent, including independent living and the social model of disability. However, equality was seen as more important than any other value. Thirdly, while the unique and core aspect of DPULOs is experiential knowledge, knowledge in 'business' development is lacking in many DPULOs, who need to upskill their workforce or attract people with such skills onto their boards. Lastly, the current definitional inadequacy of a DPULO is highlighted as focusing on internal characteristics at the expense of external power relations between DPULOs and their key funders, for example, local authorities.

8.6 Summary

This chapter initially discussed the key factors in the establishment and development of DPULOs from the mid-1970s onwards. The research demonstrated that the DPULOs established in the 1980s were formed by disability activists as campaigning organisations and have remained true to their founding principles. In contrast, the DPULOs established in the 1990s and the 2000s were formed as a result of government initiatives that promoted independent living services to improve the lives of disabled people. However, the research demonstrated that the DPULOs established towards the end of the 2000s had not yet fully formalised their structures and services.

In addition, this chapter investigated the characteristics of DPULOs by using the concepts of 'power', 'values' and 'knowledge' (SOL, 2009, cited in Bott, Sweeny and Watts, 2013). The research demonstrated that the ODI's criteria was based on the internal power created as a result of disabled people being in control of DPULOs. However, the effective external power was controlled by local authorities and other organisations. In addition, the ODI criteria primarily defined the internal values of DPULOs as the social model of disability and the principle that such organisations should be user-led. However, the ODI did not consider the external values such as equality and independent living that were seen as being necessary to improve the

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lives of disabled people. The concept of charitable fundraising was ethically unacceptable to the majority of DPULOs. However, this view resulted in a potential loss of income that such funding sources might provide for these organisations.

The wealth of knowledge within DPULOs about the lived experience of disabled people was vital in the development of independent living services. However, DPULOs lacked the essential professional and business skills necessary to compete with other organisations in local authority contract commissioning processes.

Finally, the chapter returned to the concepts of 'power', 'values' and 'knowledge' (SOL, 2009, cited in Bott, Sweeny and Watts, 2013) to investigate the factors that might help support the future security of DPULOs. The research identified five key factors:

1. The ODI incorporating the external structures and values identified in this research into their definition of a DPULO (ODI, 2011, cited in Bott, Sweeny and Watts, 2013), thus influencing national government in providing funding to improve the professional and business skills of the senior staff and management boards within the organisations.
2. The establishment of working partnerships between DPULOs to help readdress the balance of power currently held by other organisations in local authority contract commissioning processes.
3. The introduction of alternative methods of obtaining income for DPULOs from sources other than that of charitable fundraising.
4. The introduction of training and development programmes to improve the professional and business skills of the senior staff and board members within DPULOs.
5. The use of innovative ways of recruiting non-disabled board members with professional and business skills into DPULOs without compromising their user-led status.

The next chapter will restate the aims and research questions for this study.

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In addition, the chapter will summarise the reasons for selecting the area of study and the choice of methods employed in the research.

There will also be a discussion concerning: my contribution to knowledge in terms of the field of disability studies; the benefits that this research will bring to the future security of DPULOs; and the advantages that being a disabled researcher brought to this study. In addition, the limitations of this research will be outlined. Finally, I will reflect on my personal journey as a result of undertaking this study and provide details of my plans for future research.

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CHAPTER 9. CONCLUSIONS

9.1 Introduction

In the last chapter, I discussed the key factors in the establishment and development of disabled people's user-led organisations (DPULOs) from the mid-1970s onwards. I also investigated the key characteristics of and the challenges for DPULOs in terms of the concepts of, 'power', 'values' and 'knowledge' (SOL, 2009, cited in Bott, Sweeny and Watts, 2013). I used these concepts to identify the factors that might support DPULOs to survive and thrive into the future.

In this chapter, I will begin by restating the aim and research questions for this study. I will then provide a brief explanation of the reasons for undertaking this study and reflect on my choice of a research design. In addition, I will state my contribution to professional practice and discuss the benefits of undertaking this study as a blind researcher.

I will also explore the limitations of this research and my contribution to knowledge. In addition, I will suggest a topic for future research before reflecting on my journey as a result of undertaking this study as a researcher with severe sight loss.

9.2 The aim and research questions for this study

The aim of this study was to identify the factors that might support the future security of DPULOs. The study explored the ways in which changes in the political, economic and policy landscapes have had an impact on the ability of DPULOs to survive and thrive.

The literature review chapters indicated that there were significant reductions in government funding to DPULOs, issues related to the marketisation of social care services and competition from national charities and business-oriented organisations. These challenges had an impact on service provision, particularly for the disabled clients already supported by DPULOs. Historically, DPULOs were dependent on local authorities for financial support and did not have the business skills or professional structures to develop the activities required to generate income in order to run dynamic and effective organisations.

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The research questions emerged from a combination of my lived experience: as a disabled person; as the chairman of a DPULO; as a trustee of a DPULO; as a full member of a DPULO; the two literature review chapters; and the conceptual framework. I was particularly keen to identify the factors that might enable DPULOs to become more sustainable in the future. Consequently, my intention was that this thesis would inform the wider disability movement as well as the academic community. The research questions were developed as follows:

- 1) What factors influenced the establishment and development of DPULOs?
- 2) What are the characteristics of and current challenges for DPULOs?
- 3) What factors might support the future security of DPULOs?

The answers to these questions formed the basis of the previous discussion chapter. I will re-articulate my core findings in my section on contribution to knowledge below.

9.3 Background to the study

The rationale for this study was based on my lived experience as a disabled person and the knowledge I gained as the chairman, a trustee and a full member of a DPULO. One of my main responsibilities as the chairman and a trustee was to ensure that my organisation remained viable and continued to offer high quality services to disabled people. However, after the financial crisis in 2008, I became increasingly concerned about the austerity measures introduced by my local authority, particularly when it came to independent living services. However, these austerity measures resulted in the creation of a market for such services. Subsequently, my organisation began to experience competition from local and national charities and service providers from both the voluntary and private sectors. This competition resulted in increased financial pressures and a struggle for my organisation to maintain and expand independent living services for its disabled clients.

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Later, I learnt that other DPULOs were experiencing similar problems, although there was agreement amongst the CEOs I spoke to that nothing could be done to improve the situation. This is why I decided to investigate the challenges being experienced by DPULOs, as a doctoral student.

As my study was located within the disability community, I felt that the transformative paradigm was appropriate for my research (Mertens, 2007; 2012). In addition, my approach was influenced by the apparent power differences suffered by disabled people compared to the rest of society (Mertens, 2012). My intention was that the outcomes of the research would result in the furthering of social justice and change within DPULOs (Mertens, 2007; 2012). As both a disabled researcher and someone who is part of the community being researched I am positioned within this paradigm. However, I recognise that although my research was informed by the wider disability movement, I led the research, and other disabled people were not actively involved in the research process itself. For these reasons, my sole claim is that my research was informed by the transformative paradigm.

My research employed a two-stage sequential design using a combination of qualitative and quantitative research methods. The findings from the stage 1 research informed the design of stage 2. Mertens (2012) confirmed that the transformative paradigm was appropriate for conducting such mixed-methods research.

In stage 1, I used semi-structured interviews as a qualitative method of data collection in order to gain a comprehensive understanding of the opinions of the CEOs from 12 DPULOs. In stage 2, I used a survey that collected quantitative and qualitative data from the population of DPULOs in order to extend the depth and understanding of the findings from stage 1 by increasing the number of participants involved in the research. The findings that emerged from the stage 2 survey were compared and contrasted with the stage 1 findings to triangulate the outcomes from the two stages of research.

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9.4 Benefits of the research

This research has the potential to offer insights into the factors that might support the future security of DPULOs to participants and others involved within the strategic management of such organisations. In addition, the approach that was used in this research will enable those stakeholders involved with DPULOs to share the recommendations detailed within this study. In turn, this might inform other interested parties about the need for change in government policy concerning disable people and their organisations.

One example of such a strategy might involve the Office for Disability Issues (ODI) incorporating the external structures and values identified in this research into their definition of a DPULO (ODI, 2011, cited in Bott, Sweeny and Watts, 2013). Such a strategy might influence national government in providing new funding initiatives to DPULOs to improve the business and professional skills of their senior staff and management boards.

As the chairman, a trustee and a full member of a DPULO, I am cognisant with the values and belief systems inherent within such organisations and the challenges they currently face. Consequently, I believe that these factors supported me in developing the ideas that underpinned this study, in the definition of the research problem and in understanding some of the concepts discussed by the participants in the stage 1 semi-structured interviews.

In addition, as a disabled person, I have experienced the effects of oppression and discrimination in many aspects of my life. Consequently, I felt that these experiences helped me to better gain access to the participants involved in my research. For example, two of the CEOs involved in the stage 1 semi-structured interviews mentioned to me that the only reason they agreed to take part in my research was because I was a disabled researcher. In addition, I believe that the fact I was disabled, a doctoral student and the chairman of Essex Coalition of Disabled People (ECDP) gave me an extra level of kudos with the ODI senior executive when I first tried to contact them.

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9.5 Limitations of the research

As well as the strengths that being a disabled person and the chairman of a DPULO brought to this study, I also had strongly-held views about the topics discussed in my two stages of research. Therefore, I attempted to challenge my views through in-depth discussions with my supervisors concerning the data that came out of the research and acknowledged where the data was not as I had expected.

The method of employing a search of internet websites and the Shaping Our Lives user network membership database (SOL, 2014) to identify suitable DPULOs and their CEOs for inclusion in the stage 1 semi-structured interviews was a limitation in the research. This was because I might have only captured those organisations that had sufficient resources to have a website and/or be included on the SOL database.

The modified version of the coding process described by Gill et al. (2013) that I used to analyse the stage 1 semi-structured interview transcripts was also a limitation in my research. This was because the analysis of the transcripts took so long to complete that I had to use an early stage version of the findings in order to design the stage 2 survey.

In terms of the stage 2 survey itself, there were limitations as I was unable to undertake a comparison between questions, particularly those based on financial data. This was because the SurveyMonkey (SurveyMonkey Inc., 2018) dataset was not accessible to my screen reading software. In addition, I found that comparisons for some areas would have been skewed. This was because less than 0.8% of the DPULOs had a total income in excess of £2 million (see chapter 7, survey question 7) whereas over 50% had total incomes of under £100,000 (see chapter 7, survey question 7).

9.6 Contribution to knowledge

My data indicated that all the DPULOs involved in the study have responded to, and been shaped by, government policy and funding. However, the date of the establishment of the DPULOs has influenced the guiding ethos of the organisations and their operational focus and this in turn, has influenced their approach to accessing funding.

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These issues need to be understood against the changing structural restraints of government rationalisation of public sector funding which has resulted in funding cuts. While most CEOs from the DPULOs ensured that their working relationship with local authorities were mutually beneficial, there were concerns regarding the marketisation of such local authority services and the subsequent financial constraints experienced by DPULOs.

In terms of the Shaping Our Lives framework (see: SOL, 2009, cited in Bot, Sweeny and Watts, 2013), the contributions from my study to this field are numerous:

(a) Power

My research identified that the ODI's definition of a DPULO was only based on the concept of internal power as the ODI did not consider the external power relationships between DPULOs and other organisations.

The study highlighted the power relationships between local authorities and DPULOs, specifically, that local authorities have a legal obligation to promote inclusion, and DPULOs support the delivery of services to achieve this objective. However, there is inequality in the balance of power because local authorities control funding. This affected DPULOs' ability to effectively campaign, particularly against those local authorities that supported their continuing survival. While this is not a unique finding (see: Borkman et al., 2009), it does confirm earlier research.

My research highlighted that these power relations were exacerbated through the austerity measures introduced following the financial crisis that started in 2008 which disproportionately affected DPULOs. This was possibly partly because so many DPULOs are small-scale organisations and that their collective experiential knowledge is either under-valued or not understood.

The external power deficits were highlighted as major challenges to DPULOs in areas such as: financial constraints; competition; and changes to contract procurement processes. My research has demonstrated that these power differences are likely to pose threats to the future security of DPULOs.

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(b) Values

My study showed that although all of the DPULOs shared common deeply-held values, namely: independent living; choice and control; equality; inclusion; and adoption of the social model of disability, the principle that such organisations should be user-led appeared to be less important as a value to the CEOs, than were the values: equality; independent living; or the social model of disability, although the importance of the social model of disability appeared to have declined for the CEOs as disabled people moved closer to achieving equality.

The study highlighted that a clear majority of the CEOs believed that charitable fundraising was ethically unacceptable and remained a contentious issue in terms of rejecting the personal tragedy theory of disability (see: French and Swain, 2004) and promoting equality.

(c) Knowledge

The insights into organisational knowledge was highly significant in terms of both the internal and external relationships of DPULOs.

In terms of the external relationships between funders and DPULOs, my research suggested that some local authorities felt that the knowledge concerning the requirements of disabled people was held within DPULOs and as such they and their staff were recognised as experts by experience.

However, my analysis also suggested that while experiential knowledge (expertise from experience) was valued by some, a critical feature of DPULOs is that they are learning together and building a collective knowledge base that remains in the group even after an individual has left the organisation. This is important for the sustainability of DPULOs, yet, this collective knowledge was either not valued or understood by policy makers.

The knowledge required within DPULOs was in two key areas: (i) experiential and (ii) skills based. The latter is a particular issue facing DPULOs as marketisation requires knowledge and skills in commercial areas in order to sell services.

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The options facing DPULOs are either/or upskilling their own workforce or recruiting non-disabled people to their boards who bring the requisite business and professional skills and knowledge.

The three concepts: 'power', 'knowledge' and 'values', intersect and are reflected by national policy changes, which have also created a market for independent living services. The CEOs were particularly concerned that larger, especially national competitors had greater financial stability than that possessed by locally based DPULOs.

The focus on internal criteria for a DPULO is, I argue, being done at the expense of recognising the external factors that affect DPULOs. Therefore, the above issues raise a more fundamental question about what it is to be a DPULO in the early 2000s. There are diverse views amongst CEOs both on the need, acceptability and role of other forms of expertise within their organisations, and on the potential flaws or pitfalls in the ODI's criteria, which do not appear to fully capture the complexities of the changing shape, not only of DPULOs but of the UK disability movement itself.

9.7 Future research

The area of research I intend to undertake after completing this doctorate is to extend my current study. The research identified some of the factors that might help support the future security of DPULOs. However, I am unclear if the introduction of these factors into DPULOs would improve access to contracts for independent living services and support the development of commercial activities within these organisations. In addition, I recognise that the majority of CEOs of DPULOs might not be aware of the outcomes of my study. Therefore, my intention is to establish a research strategy that both informs CEOs from DPULOs about the outcomes of my research and initiates a discussion concerning the value of the factors that might help support the future security of their organisations (Morgan, 2006; Parahoo, 2006; Gill et al., 2008).

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Gill et al. (2008, p.294) suggested that focus groups could provide feedback results to research participants. Consequently, focus groups are one of the ways that the outcomes of my research could be disseminated to CEOs from DPULOs and their stakeholders. This would fulfil the intention of offering copies of my core thesis to the CEOs who took part in the original research.

Morgan (1996, p.130) defined focus groups as 'a research technique that collects data through group interaction on a topic determined by the researcher'. The aim of the focus groups would be to obtain feedback from the CEOs about the value of my research to the future security of their organisations. In addition, I would be interested to learn about whether the CEOs intended to incorporate any of the factors I detailed in my study into their DPULOs and if they have other suggestions for organisational development based on my findings. Gill et al. (2008, p.297) stated that one of the purposes of a focus group was to 'clarify, extend, qualify or challenge data collected through other methods. In addition, Morgan (1996, p.130) suggested that the 'researcher's active role' was in 'creating the group discussion for data collection purposes'.

One of the ways in which I could limit my influence on the participants would be to use a research stage called the 'back-talk focus group' that 'stimulates the reflexivity of the researcher by allowing them to generate new data' (Frisina, 2006, p.1). Parahoo (2006, p.292) defined reflexivity as 'a continuous process whereby researchers reflect on their preconceived values and those of the participants, such as reflecting on how data collected will be influenced by how the participants perceive the researcher.' I feel that the concept of reflexivity will be important in the context of my management of the focus groups, considering the knowledge I gained as a result of my connection to the two previous stages of research.

In addition, Frisina (2006, p.1) claimed that a back-talk focus group also 'empowers participants by allowing them greater power in the research process' and 'ensures responsible dissemination of potentially sensitive issues to a potentially diverse and highly politicised audience.' A back-talk focus group will be an appropriate research method to use with participants from organisations that had a highly controversial and politicised past (see for instance: Oliver, 1990; Shakespeare, 1993; Campbell and Oliver, 1996; Charlton, 2000).

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9.8 The research journey

When thinking about my research journey, I will be eternally proud of the fact that I was the first severely sight-impaired (blind) student at Anglia Ruskin University (ARU) to have completed a doctoral thesis. Reflecting on my research journey as a whole, I am not surprised that this was the case because I had to continually fight to overcome the barriers I faced in areas that I am sure my peers regarded as natural in the progression of their doctoral studies.

The area that caused me the most frustration was in accessing academic literature and other materials that were essential for the completion of my thesis. For example, in spite of the recent proliferation in the availability of digital texts, I still experienced significant issues accessing information to support the completion of my research. In particular, I spent many fruitless hours attempting to access PDF versions of articles from academic journals, only to find that my screen reading software was totally baffled by the formatting within the PDF documents.

Similarly, the forms required to successfully progress through the doctoral process appeared to be designed by ARU staff such that they could only be completed by sighted people. Consequently, I frequently required support from others because I was unable to locate explicit areas of official forms to employ my screen reading software.

Other accessibility issues that had a severe impact on my progress were the barriers I faced within the programme of doctoral training. I was particularly concerned about the ability of some academic members of staff who appeared to be unable to offer an inclusive level of teaching. Consequently, I decided that rather than wasting my time attending inaccessible training, I would undertake independent learning using the notes that accompanied the training along with using the internet to enhance my knowledge and skills in the areas being taught.

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However, it is not my intention here to single out ARU as being a particularly good or bad example of an institution that is supposed to offer accessible learning. Indeed, these are just my own lived experiences that are probably typical of those problems faced by disabled students in other similar institutions that are based on a microcosm of society as a whole. My solution to the barriers I faced was to apply the strategies I employ in my everyday life to gain a semblance of equality with others in society.

As a result, my overall view of the research journey was that it was a fulfilling and worthwhile learning experience to be a doctoral student. For example, as a long-term member of the UK disability movement, I was intrigued by the requirement for me to re-evaluate my ideas concerning the work undertaken by the activists involved in organisations such as the Union of the Physically Impaired against Segregation (UPIAS). In particular, I was pleased to learn that one of these activists, Paul Hunt, had far more involvement in the development of the UK disability movement than I first thought. Indeed, I did not actually realise that he was responsible for the UPIAS (1976) Fundamental Principles of Disability (see: Finkelstein, 2001). In addition, I really enjoyed the process of improving my knowledge and skills in areas such as the choice of an appropriate paradigm in which to position my research and undertaking a range of in-depth semi-structured interviews and a survey that might eventually result in the future security of DPULOs.

9.9 Summary

I believe that my contribution to knowledge within the field of disability studies was the most important outcome in my time as a doctoral student. I would frame my core contribution using the threefold framework of power, values and knowledge (SOL, 2009, cited in Bott, Sweeny and Watts, 2013) as follows:

Power

My research shows that power has shifted over time but during economic austerity, finance and 'value for money' takes precedence over valuing experiential knowledge, leaving DPULOs vulnerable.

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Values

Although the age of DPULOs appear to have an effect on their core vision, some values remain consistent such as independent living and the social model of disability. However, my data suggests that the concept of equality is seen as more important and has implications for who gets involved in DPULOs and that as equality is foregrounded the limitations of the social model are exposed.

Knowledge

While the unique and core aspect of a DPULO is experiential knowledge, other forms of knowledge such as knowledge and skills in business development is lacking in many DPULOs who either need to upskill their workforce or attract people with these skills onto their boards.

The three concepts above reflect the current inadequacy of the ODI's definition of a DPULO. The ODI's definition focuses on the internal characteristics of a DPULO at the expense of understanding the external power relations between DPULOs, funders (usually local authorities) and other organisations involved in contract-commissioning processes to run independent living services.

Therefore, my research suggests that for DPULOs to survive and thrive, the ODI needs to move beyond mechanistic criteria for what constitutes a DPULO and acknowledge the wider changes both within, and external to, DPULOs that reflect contemporary circumstances as well as changes within the disability community as a whole. With these factors in mind, disabled people's user-led organisations could enjoy the prospect of moving towards a secure future.

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APPENDICES

APPENDIX 1: INTERVIEW PROTOCOL

A. Before the interview.

1. Welcome the participant and initiate introductions.
2. Make sure that the participant is comfortable and happy with where the interview is taking place.
3. Make sure that the participant has read the participant information sheet and understands what the research is about.
4. If not, allow the participant time to read the participant information sheet and ask questions about the research.
5. Stress that the interview is confidential and no information about them or their organisation will be revealed as a result of them taking part in the research.
6. When the participant is ready to continue, ask them to sign the consent form.
7. Give the participant as long as they want to read the consent form and let them ask questions about informed consent.
8. Make sure that the participant is aware that they can withdraw from the interview at any time.
9. Make sure that the participant is aware of the withdrawal form.
10. Let the participant know that the interview is scheduled to last for about one hour.
11. Let the participant know that they can stop the interview or take a break at any time.
12. Let the participant know that if they are not comfortable with any question then it can be omitted from the interview.

APPENDICES

13. Let the participant know that the interview will be recorded.
14. Stress that if any personal details about them or their organisation is revealed during the interview, it will be anonymised in the final written transcript.
15. Stress that the recorded interview and transcript will be kept in a secure area and destroyed when the study is complete.
16. Ask the participant if they have any questions about the interview and whether they are ready to continue.

B. The interview

1. Can you tell me a little bit about your organisation?

(prompt) when was your organisation established, by whom and why?

(prompt) what are your organisations ethos and values?

(prompt) what services does your organisation offer?

(prompt) what is your organisations management board profile?

(prompt) what is your organisations staff profile?

(prompt) what is your organisations membership profile?

(prompt) what is your organisations legal structure?

2. What challenges does your organisation currently face?

(prompt) what skills and resources have helped you overcome these challenges?

3. What factors do you believe make your organisation professional?

4. What do your stakeholders require of you in order to see you as professional?

(prompt) have these requirements changed over time?

5. What opportunities are there for your organisation in the future?

6. Are there any other comments you want to make about your organisation?

APPENDICES

C. After the interview

1. Thank the participant for their time and for taking part in the interview.
2. Let the participant know that the interviews form stage one in a two stage study.
3. Let the participant know that copies of the thesis or an executive summary will be available at the end of the study.
4. Thank the participant again for taking part and end the interview.

APPENDICES

APPENDIX 2: LETTER OF INTRODUCTION (a), PARTICIPANT INFORMATION SHEET (b) AND CONSENT/WITHDRAWAL FORM (c)

(a)

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

[REDACTED]
[REDACTED]
[REDACTED]



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30th January 2012.

Dear Sir or Madam,

I am writing to ask if you would consider taking part in the first stage of a research study I am conducting later this year. The aim of the study is to identify the factors that might support Disabled People's User led Organisations (DPULOs) to survive and thrive into the future. I am interested in what Chief Executive Officers (CEOs) from these organisations think about this and how these factors might play a role in the future development of their DPULOs.

As a trustee and the Chairman at the Essex Coalition of Disabled People (ECDP), I am very interested in the continuing success of DPULOs and how we might help support the future security of our organisations.

I do hope you will be interested in the research I am planning to undertake and would like to take part. However, before you decide, please read the accompanying participant information sheet, which will give you further information about the study.

APPENDICES

Thank you very much for reading this letter and I hope to hear from you soon.

Yours Sincerely,

Steven Carey

Enc.

APPENDICES

(b)



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1.1 PARTICIPANT INFORMATION SHEET

1.1.1 Section A: The Research Project

1. Title of project

‘Towards the emergence of ‘professionalisation’ in disabled people’s user led organisations (DPULOs)’

2. Purpose and value of study

The purpose of this study is to investigate Disabled People’s User led Organisations (DPULOs) in the United Kingdom (UK) using the themes: historical roots; structures and characteristics; key challenges; and future opportunities. Since the economic downturn in 2008, Local and National Government financial restraint has resulted in a reduction of funding to these organisations. This has created a market for social care services and has resulted in competition between DPULOs, local and national charities and service providers from both the voluntary and private sectors. Resultant changes in power relationships between DPULOs and their financial stakeholders has created an environment where DPULOs have found it increasingly difficult to maintain and expand services to their clients and to remain viable.

APPENDICES

The aim of the study is to identify the factors that might support such organisations with complex values and belief systems to survive and thrive into the future.

This study has the potential to offer insights concerning the future security of DPULOs to participants and others involved in the strategic management of these organisations. The approach that will be used in the study will also provide an opportunity for key stakeholders to share good practice and could potentially inform other interested parties about the need for new Government funding and change within DPULOs.

3 Invitation to participate

I am inviting you to take part in stage 1 of a two-stage research study. Before you decide to take part, it is important that you understand why I am undertaking the research and what will happen if you get involved. Please take some time to read this information sheet and discuss it with others if you wish (the information is also available in other formats).

If anything is not clear or you need more information, please ask. If you do decide to take part, could you please contact me within two-weeks of receiving this letter and information sheet.

4. Who is organising the research?

I am a doctoral student at Anglia Ruskin University. I am registered as severely sight impaired (blind) and self-prescribe as a disabled person. I have been a trustee of the Essex Coalition of Disabled People (ecdp) for eleven years and the Chairman since 1996.

5. What will happen to the results of the study?

The results of the study will be used to identify factors that might support the future security of DPULOs. The study will form part of a doctoral thesis and will lead to the award of a PhD. The study is due to be completed in March 2019.

APPENDICES

6. Source of funding for the research

This study will be self-funded. However, some of the fees will be paid by two charities that support disabled students studying in higher education: the Snowdon Trust and the Gardner's Trust.

1.1.2 Contact for further information

Response	Percentage
U.S. should take action	85%
U.S. should not take action	15%

APPENDICES

1.1.3 Section B: Your Participation in the Research Project

1. Why you have been invited to take part

You have been invited to take part in this study because you are the Chief Executive Officer (CEO) of a DPULO. You are one of twelve CEOs who have been asked to participate in this research. Your help will be valuable in providing the findings for the first of two stages of research in this study. Stage 2 of this research will be a survey of the CEOs of the population of DPULOs in the UK.

2. Whether you can refuse to take part

Yes, it is your decision whether or not you take part. If you do decide to take part, you will be given a copy of this information sheet to keep. You will also be asked to complete a consent form and give verbal consent when the research takes place.

3. Whether you can withdraw at any time, and how

If you do not want to take part or decide to withdraw from the research, you can do this at any time. If you want to withdraw, please contact me to let me know. You will be given a withdrawal form that can be completed and returned in the stamped addressed envelope provided. If you do not want to take part or decide to withdraw from the research, you will not be affected in any way.

4. What will happen if you agree to take part

If you decide to take part, you will be asked to take part in an interview at a time convenient to you. The interview can be either face-to-face at a place of your choice or by telephone. The interview will last for approximately one hour and I will ask you:

General questions about the history, structure, values and operation of your organisation.

The perspective you place on professionalism within your organisation.

APPENDICES

The challenges faced by your organisation.

The future opportunities for your organisation

The strategies planned for the future development of your organisation.

For access purposes, I would like to record the discussion and will ask your permission before the interview begins.

5 Whether there are any risks involved (e.g. side effects from taking part) and if so what will be done to ensure your wellbeing/safety

It is unlikely that any risks will occur as a result of taking part in this research. You can take as long as you wish to answer the questions and you can ask for a break at any time during the interview. I am a disabled person myself and will be very understanding about your access needs. A risk assessment has been completed for this stage of the research.

6. Agreement to participate in this research should not compromise your legal rights should something go wrong

7 Whether there are any special precautions you must take before, during or after taking part in the study

There are no special precautions you need to take before, during or after the research takes place.

8. What will happen to any information/data/samples that are collected from you

This research will conform to the Data Protection Act (1998). The information I collect in the interviews will be transcribed and then analysed along with the other eleven interviews to obtain your perspective on the areas detailed in 4 above. The views from your interview will be used in the design of a survey of the CEOs from the population of DPULOs in the UK. The interview transcripts will be anonymised. All paper information will be kept secure in locked filing cabinets and digital information will be kept on a password protected computer.

APPENDICES

9. Whether there are any benefits from taking part

There are unlikely to be any personal benefits from taking part in this study. However, there is an opportunity for you to potentially contribute to a wider body of knowledge about the future security of DPULOs.

10. How your participation in the project will be kept confidential

Anything that you say during the interview will be strictly confidential. Any information that you give will be transcribed in such a way as to ensure that neither you or your organisation can be identified. The audio version of your interview will be destroyed after it has been transcribed. The transcript will be kept in a password protected computer. I will be the only person with access to the computer password. All paper information will be kept in a locked filing cabinet and destroyed after the study has been completed. If you want a copy of the audio version of your interview, please ask and one will be sent to you.

YOU WILL BE GIVEN A COPY OF THIS TO KEEP, TOGETHER WITH A COPY OF YOUR CONSENT FORM

APPENDICES

(c)



**Anglia Ruskin
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www.anglia.ac.uk

NAME OF PARTICIPANT:

Title of the project: Towards the emergence of 'professionalisation' in disabled people's user led organisations (DPULOs)

Main investigator and contact details:

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

Members of the research team:

Professor Carol Munn-Giddings.

Dr Pauline Lane.

1. I agree to take part in the above research. I have read the Participant Information Sheet which is attached to this form. I understand what my role will be in this research, and all my questions have been answered to my satisfaction.

APPENDICES

2. I understand that I am free to withdraw from the research at any time, for any reason and without prejudice.
3. I have been informed that the confidentiality of the information I provide will be safeguarded.
4. I am free to ask any questions at any time before and during the study.
5. I have been provided with a copy of this form and the Participant Information Sheet.

Data Protection: I agree to the University⁴ processing personal data which I have supplied. I agree to the processing of such data for any purposes connected with the Research Project as outlined to me*

Name of participant (print):

Signed _____

Date: _____

YOU WILL BE GIVEN A COPY OF THIS FORM TO KEEP

If you wish to withdraw from the research, please complete the form below and return to the main investigator named above.

Title of Project: 'Towards the emergence of 'professionalisation' in disabled people's user led organisations (DPULOs)'

⁴ "The University" includes Anglia Ruskin University and its partner colleges

APPENDICES

I WISH TO WITHDRAW FROM THIS STUDY

Signed: _____

Date: _____

APPENDICES

APPENDIX 3: THE PERSONAL INTRODUCTION FROM THE ODI SENIOR EXECUTIVE (a) AND MY PARTICIPANT LETTER (b)

(a)

Date: 21st January 2014

Dear Mr Carey,

I am the National Lead for the Strengthening Disabled People's User Led Organisations (DPULOs) Programme, which is run from the Office of Disability Issues in the Department of Work and Pensions.

I support the research that you are doing and I look forward to reading it since it is so closely aligned with the objectives of the Strengthening DUPLOs Programme.

In my role as National Lead I have responsibility for a database containing the contact details of DPULOs. I do not require permission to use this database.

I (or someone from my team) will send your survey to the organisations in this database.

I am happy to act as gatekeeper for your research and I (or members of my team) are happy to prompt potential participants if responses are low.

Yours sincerely,

Rachael Wallach
Strengthening DUPLOs Programme

APPENDICES

(b)

Dear Participant,

I am a blind researcher based at Anglia Ruskin University in Chelmsford, Essex and identify as a disabled person. I have also been the chairman and a trustee of an Essex based Disabled People's User Led Organisation (DPULO) for the last 13 years. I am currently conducting research into professionalism in DPULOs .

As the Chief Executive Officer (CEO) of a DPULO, you are kindly invited to take part in this survey. The survey forms the second stage of a 3 stage PhD research project, entitled 'Towards the Emergence of Professionalism in Disabled Peoples User Led Organisations (DPULOs)', that is scheduled for completion in 2017. Stage 1 of the research project consisted of semi-structured interviews with CEOs from 12 DPULOs. The findings of Stage 1 have informed the current stage of the project. Stage 3 will be a focus group of a random selection of CEOs that is scheduled to take place later in 2014.

The purpose of the research project is to identify the challenges currently being faced by DUPLOs and to explore how and if organisations with complex values and belief systems can maintain and improve service provision in an increasingly difficult economic environment. In addition, the research will offer insights concerning the establishment of professionalism in DPULOs. The survey is made up of 28 questions and should take no more than 20 minutes to complete.

The survey is anonymous and any information that can be used to identify you or your organisation will be removed. If you do not wish to answer a specific question then please move on to the next one. The survey data will be kept on a password protected computer and will be destroyed at the end of the research project. It is assumed that you have given your consent to take part in the research project if you partially or fully complete the survey. The survey will close at 5 PM on Friday xxx xxx 2014.

This stage of the research has been given formal approval by the Anglia Ruskin University Research Ethics Committee. If you have any questions or have problems in completing the survey, please do not hesitate to contact me by using the following details.

APPENDICES

[REDACTED]

If you require confirmation of my status as a research student at Anglia Ruskin University then please contact my Research Supervisor:

[REDACTED]

Can I take this opportunity to thank you for taking part in this research project.
To begin the survey please click the link below
:

APPENDICIES

APPENDIX 4: A COPY OF THE FINALISED SURVEY

Part 1: The Origin, structure and characteristics of DPULOs.

Question 1: When was your organisation established as a DPULO

(please choose one)?

Before 1980

Between 1980 and 1989

Between 1990 and 1999

Between 2000 and 2009

After 2009

Question 2: In what area of the United Kingdom is your organisation located

(please choose one)?

London

South East

South West

West Midlands

East Midlands

North West

North East

Wales

Northern Ireland

Scotland

Question 3: What percentage of your trustee/director board do you consider identify as disabled people? (please choose one)?

0% to 24%

25% to 49%

50% to 74%

75% and over

APPENDICIES

Question 4: Does your organisation have a commitment to recruit disabled people: on to your management board; as staff; and as volunteers?

A: Management board.

Yes

No

B: Staff.

Yes

No

C: Volunteers.

Yes

No

Question 5: Are you actively working towards recruiting disabled people to your organisation?

Yes

No

Question 6: Please could you name two key values, established by the UK disability movement, that you consider to be important to your organisation?

Value 1.....

Value 2....

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Part 2: Income

Question 7: Please could you provide details of your organisation's total income, from all sources, for the financial year 2012/13 (please choose one)?

Less than £50,000

Between £50,000 and £100,000

Between £100,000 and £250,000

Between £250,000 and £500,000

Between £500,000 and £1,000,000

Between £1,000,000 and £2,000,000

Over £2,000,000

Question 8: Since 2010, has your organisation received income from the following sources and, if the answer is 'Yes', how has that income changed?

A: Government CONTRACTS

Yes

No

If you answered 'Yes', how has your income been affected?

Increased

Neither increased nor decreased

Decreased

B: Government GRANTS.

Yes

No

If you answered 'Yes', how has your income been affected?

Increased

Neither increased nor decreased.

Decreased

APPENDICIES

C: Grants from foundations and other grant making organisations.

Yes

No

If you answered 'Yes', how has your income been affected?

Increased

Neither increased nor decreased.

Decreased

D: Income from investments and legacies.

Yes

No

If you answered 'Yes', how has your income been affected?

Increased

Neither increased nor decreased.

Decreased

E: Income from commercial enterprise

Yes

No

If you answered 'Yes', how has your income been affected?

Increased

Neither increased nor decreased.

Decreased

APPENDICIES

Question 9: Since 2010, have you found it necessary to use your financial reserves to support your organisation's activities?

Yes

No

Part 3: Key Challenges for DPULOs

Question 10: Please indicate the level of concern for your organisation's future ability to provide services, with reference to the following issues.

Time writing bids:

No Concern

Low

Mid

High

Strategic planning processes:

No Concern

Low

Mid

High

Staff and Volunteer Recruitment / Retention

No Concern

Low

Mid

High

The viability of your organisation:

No Concern

Low

Mid

High

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Competition from businesses and other charities:

No Concern

Low

Mid

High

Changes to Local and National Government commissioning processes:

No Concern

Low

Mid

High

Question 11: Does your organisation experience problems in recruiting disabled people to serve on your management board?

Yes

No

**Question 12. What skills are lacking in your organisation?
(please tick all that apply)**

Organisational governance

Strategic management and business development

Financial management

Human resources and workforce management

Marketing and sales

Communication and public relations

Legal

Commissioning and procurement

Income generation

Health and safety

Quality standards

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Question 13: Does your organisation offer an appraisal scheme to: your trustee/director board; your staff; and your volunteers?

Yes

No

Question 14: Do you offer training and development opportunities to all members of your workforce?

Yes

No

Question 15: Does your organisation operate a recognised Quality Management System (QMS) (for instance: ISO 9001, PQASSO, Investors in People or similar)?

Yes

No

Question 16: Do you seek feedback from your clients to monitor the quality of the services offered by your organisation?

Yes

No

Question 17: Does your organisation operate a complaints procedure

Yes

No

APPENDICIES

Question 18: How many commercial enterprises have purchased a service or services from you over the last twelve months?

Please state....

Question 19: Has your organisation experienced competition with other DPULOs ?

Yes

No

Question 20: Does your organisation consider it ethically acceptable to undertake charitable fundraising (for instance: street collections, telephone donations or similar activities)?

Yes

No

Question 21: Please provide any additional comments about current challenges and/or future opportunities for your organisation

Comments:

.....

.....

.....

Please note that this survey is anonymous. Any information that can be used to identify you or your organisation will be removed. The survey data will be kept on a password protected computer and will be destroyed at the end of the research project.

APPENDICIES

Thank you very much for completing this survey. Your contribution towards the research project is very much appreciated. Again, if you have any questions about the survey, then please contact me by using the following details

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

APPENDICES

APPENDICES

APPENDIX 5: ETHICS APPROVAL LETTER

15 February 2012



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Dear Steven,

Re: Application for Ethical Approval

Project Number: 11/045

Project Title: 'Towards the emergence of 'professionalisation' in disabled people's user led organisations (DPULO's)'

Principal Investigator: Steven Carey

Thank you for your application for ethical approval which was considered by the Faculty Research Ethics Panel (FREP) at its meeting on 13 February 2012.

I am pleased to inform you that your research proposal has been approved by the Faculty Research Ethics Panel under the terms of Anglia Ruskin University's *Policy and Code of Practice for the Conduct of Research with Human Participants*. Approval is for a period of three years from 15 February 2012.

It is your responsibility to ensure that you comply with Anglia Ruskin University's Policy and Code of Practice for Research with Human Participants and specifically:

- The procedure for submitting substantial amendments to the committee, should there be any changes to your research. You cannot implement these changes until you have received approval from FREP for them.
- The procedure for reporting adverse events and incidents.
- The Data Protection Act (1998) and any other legislation relevant to your research. You must also ensure that you are aware of any emerging legislation relating to your research and make any changes to your study (which you will need to obtain ethical approval for) to comply with this.
- Obtaining any further ethical approval required from the organisation or country (if not carrying out research in the UK) where you will be carrying the research out. Please ensure that you send the FREP Secretary copies of this documentation.

APPENDICES

- Any laws of the country where you are carrying the research out (if these conflict with any aspects of the ethical approval given, please notify FREP prior to starting the research).
- Any professional codes of conduct relating to research or research or requirements from your funding body (please note that for externally funded research, a project risk assessment must have been carried out prior to starting the research).
- Notifying the FREP Secretary when your study has ended.

Information about the above can be obtained on our website at:

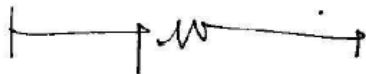
<http://web.anglia.ac.uk/anet/rdcs/ethics/index.phtml/>

Please also note that your research may be subject to random monitoring by the committee.

Please be advised that, if your research has not been completed within three years, you will need to apply to our Faculty Research Ethics Panel for an extension of ethics approval prior to the date your approval expires. The procedure for this can also be found on the above website.

Should you have any queries, please do not hesitate to contact me. May I wish you the best of luck with your research.

Yours sincerely



Dr Leslie Gelling
For the Faculty (of Health, Social Care & Education) Research Ethics Panel

T: 0845 196 2529

E: leslie.gelling@anglia.ac.uk

cc:

Dr Tim Schafer (FREP Sponsor)
Prof. Carol Munn-Giddings (Supervisor)
Beverley Pascoe (RESC Secretary)